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**SOMEBODY'S CHILD: AN EXPLORATION
OF THE CONTRIBUTION MADE BY
BULGARIAN GRANDMOTHERS TO THE
DE-INSTITUTIONALISATION OF
DISABLED CHILDREN**

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PhD

2018

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requirements of the University of Northumbria at
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Abstract

The practice of placing children without parental care in large institutions has a long history as a global phenomenon. Since the 1950s a continuous stream of research has highlighted the harmful effects of institutional life on children's development. Babies, young children, and children with impairments are recognised as being particularly vulnerable. Whilst other European countries have developed alternative care based around models of caregiving within 'the family', Bulgaria and other Central Eastern European countries have been slow to develop de-institutionalisation.

This thesis explores the role of local grandmothers (Babas) who are paid a small remuneration to provide one to one care for disabled children in a large institution in Bulgaria. Taking an ecological approach to children's development, the study situates the child's experience within the wider socio-political context which highlights how practices have been informed by dominant political and historical ideologies. The research applies a qualitative methodology, informed by the critical research traditions of Feminism and Disability Studies. Data was collected using semi structured interviews from Babas, Bulgarian professionals and British volunteers who have worked together in the institution and non-governmental organisations (NGO). In addition, documentation from one NGO was analysed.

Key findings show that the Babas offer an alternative caregiving experience for these children. The daily intimate encounters between the Babas and children transform the child's immediate crucible of development. They move from an isolated and stagnant space of organisational caregiving practices at odds with their needs and human rights, to an active space of intimate and responsive caregiving practices which promote development, resilience and agency. Overall the Baba offers the psychological investment in the child that is absent in the institution and offers support at a key transitional point.

In conclusion, the findings of this project are not presented as a definitive solution to the complex problem of the institutionalisation of children. However, it does propose that the Baba programme is a significant part of the transformative process for wider improvements in the provision of alternative care for these children. This supports the development of de-institutionalisation policies and strategies within Bulgaria and stresses the significance of developing and embedding interventions in meaningful ways within local communities and cultures.

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee on 25th October 2011.

I declare that the Word Count of this thesis is 84, 047 words

Name: Lindey Louise Cookson

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Date: 10th May 2018

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Dedication

I couldn't possibly write a thesis about grandmothers without thinking about my own. Writing this took me back to many memories of even the smallest expressions of 'love' and 'belonging' that I was blessed with as a child from my 'Grandma Mabel' and 'Nana Cookson'. This is dedicated to their memory.

This thesis is also dedicated to all of the children I have met in the institutions in Bulgaria, especially the children from Institution X. I really do live in hope that life becomes kind for you, and that you get to spend days playing in the sunshine in your beautiful country. It is also dedicated sadly, in memory; to the children I knew and cared for, whose way out of Institution X was death.

“Love is the only way to grasp another human being in the innermost core of his personality. No one can become fully aware of the very essence of another human being unless he loves him. By his love he is enabled to see the essential traits and features in the beloved person; and even more, he sees that which is potential in him, which is not yet actualised but yet ought to be actualised. Furthermore, by his love, the loving person enables the beloved person to actualise these potentialities. By making him aware of what he can be and of what he should become, he makes these potentialities come true.”

(Viktor Frankl, 2004:57)

Chapter One

Introducing the Study

1.1 Introduction

This research explores the work of a project known as the Baba project which introduces alternative caregiving practices to disabled children in a large scale residential institution for babies and young children (hereafter Institution X) in Bulgaria. The project offers a small remuneration to local grandmothers, known as Babas, hence the name of the project, who care for the children on a long term basis for two hours each day. It is funded from charitable donations managed by Non-Government Organisations (NGOs) based in Bulgaria and in the UK. The study is primarily concerned with exploring the role of the Babas and investigating their potential to contribute to the de-institutionalisation of the children.

The purpose of the study is to contribute to global dialogue, discussions and debate about institutional care and alternative practices for children without parental care, particularly disabled children, and their rights, to generate a new contribution to knowledge in this area and to have a positive impact on policy and practice. The background to the study is that it developed as a consequence of my personal volunteering experiences in Bulgarian institutions. In analysing and exploring this experience, and in offering research intended to support the Babas' work with the children, I draw upon a number of disciplines and areas of research, those being Early Years (in particular, developmental theory), Childhood Studies and Disability Studies as all offer useful conceptual lenses.

1.2 Setting the Scene.

In 2010, aged 46, I made what has proved to be a life changing decision. Using personal contacts and networks I arranged a one month placement for myself as a volunteer in Institution X. In addition, as an academic in the field of Early Years and Childhood Studies, I worked with a Bulgarian contact to offer the same volunteering experience to a group of 17 undergraduate students. This initial one month period

spent volunteering in Institution X was significant for both the students and myself in shaping future careers and thinking about and researching childhood both nationally and internationally, particularly in relation to children's rights, child development and the de-institutionalisation policies in Bulgaria. This first experience led to my making a series of further visits to Institution X and also to other small and larger scale Bulgarian institutions, enabling me to develop my understanding of the national context for both caregiving practices and institutionalisation. Further, it led to my becoming a volunteer co-ordinator and, in turn, led to the development of this PhD study.

1.3 My First Encounter with Institution X

The institution is, in many ways, typical of its type, making it an appropriate focus for study. It is a large grey concrete building with eight 'areas' split over six floors, on a large site with overgrown gardens and surrounded by a high concrete wall and metal fence. Unlike many institutions in Bulgaria however, it is situated in a central location within a large town, rather than a more rural location, something I discuss later. At the beginning of my volunteering in 2010 Institution X was home to over 250 children¹. Children are divided amongst areas according to age group apart from children with impairments who live on the very top floors in two large sections similar to hospital wards, which, for the remainder of this thesis will be collectively called Area A. The focus of this study was specifically on the Babas working with children from Area A.

Before visiting Institution X, my intention had been to develop a 'play project' to be implemented by myself and the students across the whole institution as I had been made aware by my contacts that all of the children spent most of their day confined to their cots with little stimulation. On the first day of a pre-volunteering fact-finding

¹ Over the years since, the number of children has decreased significantly as a result of the de-institutionalisation process in Bulgaria.

mission intended to help me develop play activities, I realised, as Moore and Dunn (1999) said of their own experiences, the extent of my 'inconceivable naivety' and 'idealistic vision' upon witnessing the actual conditions the children lived in. Like both authors (ibid) commenting on visiting the children in Romanian orphanages, I questioned how I could ever contribute realistically to any type of positive changes in these children's lives. However, I remained determined, and developed a different induction project to that which I had originally been planning for the student volunteers. The play activities became simple sensory development activities and the primary aim became to get the children out of their cots as often as possible, preferably taking them out of the institution for fresh air and physical activity.

From my observations during this initial visit, it was evident that across all sections of the institution the children had experienced varying levels of developmental harm in every area; cognitive, physical, social and emotional. I discovered, from my informal conversations with key staff members, that in some cases these children had entered institutional care as children without impairments. This suggested that their developmental delay and impairments could be a direct consequence of the features of institutional care. This implied that institutional care for children in Area A might be yet more problematic given that Area A was home for them from the point that they were 'diagnosed' with impairment labels including Down's Syndrome, Cerebral Palsy, and Epilepsy either at birth or very soon afterwards.

It was also during this first 'fact finding' visit that I became aware of the NGO funded project employing local grandmothers to work on a one to one basis with these children, which aimed to encourage the formation of meaningful attachments and enhance overall development. From conversations with staff attached to the project, I found out that when this particular project was developed, the organisers decided that the children in Area A should be prioritised. I was informed by a Bulgarian

professional working with Institution X that many of these children were extremely unwell and for some of them the care might be palliative. This was a common feeling amongst the institutional team. Generally, it was believed that a Baba would introduce some more intimate care developed specifically around the individual needs of each child, with the purpose of providing positive encounters which would help the children to build up trust and experience attachments. The impact of the Baba programme was anecdotally recounted to me by staff who said that children who received a Baba started to respond positively; they were growing and appeared to have better general health, and began to smile and respond to their Babas in ways which had not been observed before. I witnessed some of these changes myself as a volunteer around the institution a few months later when I volunteered for the first time for a period of 4 weeks, and also in subsequent visits.

During these early visits I also became aware that similar types of baba programmes were developed and running in other institutions as well as within Institution X. However, this was the first of its kind to work with the disabled children. In this baba project every Baba has two children who she spends two hours each day with, on a one to one basis. The Baba is part of a small team including 2 psychologists and 2 physiotherapists. The Babas are local women who are interviewed and undergo a small amount of training from the psychologists. During holiday periods British volunteers were also part of this project.

Volunteering was a very emotional experience for me, especially during the first month, which I dealt with by writing at the end of most working days, so establishing a reflective practice which continued throughout my four years of work with Institution X and others like it. Over this period I produced a series of notebooks, memos and other materials in a number of formats, including drawings and photographs (taken with permission and only shared with others for the purpose of volunteer training).

Additionally, other people contributed to this emotionally charged data, such as the student volunteers who shared their poetry and other personal writings with me. The critical incidents and reflections captured in my notebooks marked the beginnings of my attempts to make sense of my experiences and of life in the institution, some of them also noting my thoughts about the Babas.

In further setting the scene for this study, I offer two extracts from my diaries. These show the high level of observation involved, reflecting both my professional skills and the intensity of the emotional experience. These extracts also suggest how these reflective diaries contribute to this research, both in the contextual information they contain, but also through the impressionistic material about the institution and the Baba programme. The process of revisiting them helped me to shape and refine the focus of the study.

Notebook entry 1. My introduction to Institution X (March 2010)

Standing outside the large, grey building- it looked like a block of government type offices built in the UK in the 1960's – 70's. I was filled with a sense of fear and dread, and worried about what I might see and how I would react. Babies first, rows and rows of babies in cots, no colours, just babies in cots, lying on their backs, most of them lying still, no crying. One baby looked like my little grandson, he was about the same age. My eyes filled up with tears at the thought of my grandson being in that cot, in the corner of that room, with all those other babies lying in cots and with no cuddles and no one to respond when he cried.

Upstairs to the next room - 'the 'sick' children' (as described by a member of staff) - as soon as I walked into the area (Area A) my senses were overloaded with the most horrible smell, a smell that I have never experienced before, and have only ever

experienced in similar institutions in Bulgaria. Myself and my colleague were both 'retching' with the smell.

There was a long corridor with connecting rooms. They were clean and the director pointed out proudly the matching bedding on all the cots. I did not want to offend the director with my response as I knew it might affect her attitude towards volunteers coming to the institution, but more importantly I did not want to offend the children, all of whom appeared to have complex impairments and high medical needs.

I was shocked that the director² proudly pointed out the matching bedding on all of the cots but did not seem to notice the unhappy, frail children lying on their backs in pools of urine and vomit staring at the white ceilings and blank walls. The exposed parts of some of the children's bodies showed severe malnourishment, dehydration and muscle atrophy. Some children were bound tightly in sheets so only their heads were free, others who were free to move were rocking or pulling at their own hair, some were just groaning, whimpering and seeming to struggle for every breath. Some of the children with hydrocephalous had huge heads on their tiny bodies. They could barely move but did show some response when spoken to and touched. I noticed the limbs of most of the children just seemed to be in the wrong place, as if they had been broken, twisted, then reset.

In the next section of Area A, I noticed the caged cots³, very high cots with thin metal bars – a child with Down's Syndrome was crawling from one end of a small caged cot to the other, the behaviour reminded me of a caged animal in a zoo. My colleague held his hands through the cot bars and sang to him. He responded by smiling, making eye contact and making grunting noises as if he was joining in. He was

² This director was replaced soon after the study began

³ Caged cots were out of use within a year of my first visit

obviously enjoying the moment. I guessed from the size of him that he was about 10-12 mths old. I later found out he was 4years old.

Another child was sitting up, her legs dangling through the spaces between the bars and her hands holding onto the bars. She began poking her hands through, using eye contact and making communicative noises as if she wanted me to stay and interact with her. I felt frustrated that the caged cot was so high I couldn't unfasten it to lift her out, all I could do was to hold her hands and talk to her through the bars. She was tiny, she looked about 18 months old and I later found out she was six. Another 'caged child' I met was in the institution (and in Area A for 'sick' children) because of a visual impairment diagnosed at birth.

Notebook entry 2. My Introduction to the Baba programme (March 2010)

As I was introduced to the children I noticed that some of them were wearing a small bracelet of woven red and white threads, with a small tassel. The Bulgarian (English speaking) psychologist who was showing us (myself and two colleagues) around the institution, explained that these children had 'Babas' who had tied these bracelets on their wrists to symbolise the Bulgarian celebration of 'Martenista', or 'Baba Marta' – a very significant Bulgarian celebration of spring and new life. It occurred to me that the very simple gesture of giving the children a bracelet implied that they belonged to the culture and community around them. The bracelet seemed to demonstrate 'belonging'. I felt happy that some of the children had 'a someone' who cared enough about them to include them in this significant Bulgarian celebration. At the same time, I was also overwhelmed with sadness for most of the children who were not wearing the bracelets, which implied (to me) that nobody cared enough about them to include them in the celebrations. This also symbolised to me at the time that they were therefore excluded from their culture and community. During the same visit the psychologist picked up a 'chubby' child and explained, "you can see which children have babas- they are fatter than the rest". I didn't realise at the time but this

(humorous) remark became memorable as I began to notice the extent to which this statement appeared to be a fairly accurate reflection of the situation. As I walked around the institution that day, I was often able to spot children who had Babas as they were wearing clothes (not institutional dungarees), and had other subtle signifiers of belonging such as hair slides in their hair. Some just looked healthier generally.

Additional extracts from some of my diary entries and personal reflections have been included as an appendix (appendix 1) and are referred to throughout the thesis.

I feel it necessary at this early point in the thesis to state that this research is not intended to portray Bulgarian people, their culture and their ways of life negatively. My experiences have led me to respect Bulgarian culture, history and tradition and I have many friends there as a consequence of my volunteering. This project *is*, however, intended as a critique of the practice of placing children in large institutions as an alternative to family care, regardless of the country or nationality of the policy makers and families involved. This reflects current global thinking around alternative care for children without parental care, which argues that ‘the international community must ensure that institutions are used only as a temporary option and in extraordinary circumstances’ (UNICEF, 2009:19).

1.4 Research context

1.4.1 Institutional Care and ‘Orphanages’

Despite overwhelming evidence highlighting the inadequate emotional and physical environment of institutional care for children, and its deleterious impact on their health, well-being and development, it continues to be used as an alternative to family care internationally. Placing children in large institutions is therefore a ‘worldwide phenomenon’ (Browne, 2009:3). Recent figures suggest that there are between 2 million and 8 million children living in institutions around the world (UNICEF, 2009;

Csaky, 2009), although these figures are unreliable and probably grossly underestimated (Carter, 2005; UNICEF, 2007; UNICEF, 2009). The problem in gaining more accurate statistics is due largely to the lack of registration of institutions in some countries and a lack of common definitions across countries when attempting to 'measure' institutional care (ibid).

A UNICEF report in 2009 stated that Central and Eastern European (CEE) countries and the Commonwealth of Independent States (CIS) had the highest numbers of children in institutional care at approximately 800,000, almost double the amount of other countries in the Organisation for the Economic Co-operation and Development (OECD) (UNICEF, 2009). Furthermore, the figures for admitting young children and children with impairments into institutions were also high across CEE/CIS countries (UNICEF, 2005; Vann and Siska, 2006; UNICEF, 2010). A report by the European Commission (2007) reported figures showing that in Western Europe 4% of children were placed into institutions because of impairment, whereas the figure was 23% in Central and Eastern European Countries and the Commonwealth of Independent States (European Commission, 2007). Bulgaria, in particular, has stood out in recent years as having the highest rates of admissions to large institutions for young children, from birth to three years, and children with impairments in Europe (Bilson, 2013; UNICEF, 2012).

These high numbers across CEE/CIS countries, including Bulgaria, exist in spite of research findings and guidance which clearly and overwhelmingly identify the largely uncontested view that the impact of institutionalisation on young children and children with impairments is severe (United Nations, 2006; Carter, 2005; Nelson et al, 2014). Specifically, it is noted that very young children and children with impairments are most damaged by the experience of institutional care (Bilson, 2009; Browne, 2009). Consistently, reports directly link the stark conditions common to most large

institutions to the developmental delay, stunted growth and emotional, behavioural and cognitive difficulties experienced by many institutionalised children (Rutter, 1998, 2007; Chisolm, 1998; Nelson et al, 2014; Save the Children, 2009).

Globally, reports from research and inquiries have increasingly made visible the stories of ‘survivors’ of institutional care. These narratives document abusive and inhumane practices towards children living in establishments set up to provide ‘safety’ for children without parental care. In many countries around the world, such reports have led to reforms and government apologies. Additionally, debates about the provision of ‘alternative’ care for children without parental care (for whatever reason), including for disabled children, are far from resolved in all countries around the world, including the UK. Maginn and Cameron, (2013: 165) remind us that,

‘The ugly truth is that in every town and city in the world, there are children and young people who have been abandoned, rejected, neglected, abused, and exploited: these children do not live in a world of well-being and opportunity, for them, life is a struggle for survival’.

1.4.2 Children, Childhood and Disability.

Ultimately, this research is about improving the care of children without parental care and therefore looks to explore the quality of the care offered by an institution as an alternative to family life. Consequently, in analysing the role of Babas and their potential to contribute towards the de-institutionalisation of the children with impairments in Area A, I draw primarily on ecological and socio-cultural approaches to understanding children’s development. These approaches contrast with traditional psychological models of child development which have tended to study the child in isolation, separated off from their social relationships and the cultural contexts of their experiences (Packer, 2017). Ecological approaches emphasise the need to understand the child as situated in the centre of an intricate and complex world of inter-related systems which have a direct or indirect influence on their development

(Bronfenbrenner, 1979; Bronfenbrenner, 1986; Super and Harkness 1986, Rogoff, 1990). In relation to this research, it is therefore necessary to take an approach which examines the wider social, economic, political, historical and cultural context of institutional care in Bulgaria. This approach reflects my agreement with Disney (2013) who, in examining 'orphan care' in Russia, emphasises that,

'while these institutions can be incredibly damaging to a child's development, they are not all the same, and it is important to develop an understanding of these different spaces in order to understand and adapt a system which in some places has not changed for decades' (2015: 33).

Specific to these former communist societies is the influence of Soviet ideologies and traditions which have played a significant role historically in the segregation of children with impairments from their peers, families and communities and have lingered in those countries even following the collapse of communism in 1989 (Ivanova and Bogdanov, 2013; Terziev and Arabska, 2017; Disney, 2013; Walker, 2011). The difficulties associated with the transition from 'state domination to more open societies' has also been noted as a challenge common to these countries (Vann and Siska, 2006: 426).

This approach also reflects other conceptual lenses underpinning the study. Although I am using an ecological approach to help to situate and understand the children's experiences, in examining the daily interactions of the Babas and children I am drawing from other development perspectives throughout, particularly 'caregiving' and concepts relating to the development of attachments, love and belonging (Bornstein and Putnick, 2012; Bowlby, 1969, 1988, 1989; Coleman-Oluwabusola, 2017). I do so in a way which also reflects a more critical position of Childhood Studies (Prout and James, 1997; Wyse, 2003) which reflects my own beliefs about children and childhood. Traditional child development approaches have not fit comfortably with

those of Childhood Studies, one of the key tensions being the very different perspectives of children and childhoods inherent in each approach. Traditional models have been dominated by developmental constructions of children as passive, helpless and dependent objects of research and from this perspective, researchers produced a dominant view of a 'universal' or 'standard child', a relatively fixed position which was frequently applied to all contexts without question (Burman, 2008). The focus of developmental psychology 'was finding ways of turning the immature, irrational and incompetent child into a mature, rational and competent adult' (Gabriel 2017:20). Childhood Studies writers present contrasting views of children and childhoods, stressing the socially constructed nature of childhood, and promoting representations of children as active, competent agents in their own lives (Smith and Greene, 2014).

However, I am aware that, as Leonard (2016) warns, there can be dangers in creating a binary opposition between child development perspectives and Childhood Studies. Further, whilst Childhood Studies has challenged traditional child development for ignoring context and social factors, it has itself been challenged for minimising the importance of children's psychological needs. There is what can be described as a messiness in the relationship between the two. So, whilst these positions appear incompatible, my approach taken in this study is positioned somewhere in between; drawing from what I consider to be the most appropriate and relevant child developmental perspectives, but considering them in such a way that remains questioning and critical of the concept of the 'universal' child. This study must remain cognisant of the need to understand the tensions within and across disciplines.

This acknowledgement of the diversity and complexity of children and childhoods is especially important given that the study is based in a Bulgarian context, when my

own experiences of children and childhoods (personally and professionally) is very much in a UK context.

Turning to Disability Studies, writers have highlighted the lack of attention paid to the experiences of disabled children in Childhood Studies literature (McLaughlin et al, 2016; Davis, 2012). Likewise, they have also challenged the way that child development perspectives have led to the medicalisation, labelling and segregation of children who have not met up to the 'norms' of the universal child (Connors and Stalker, 2006).

In his discussion of disabled children and inclusive education, Mitchell (2005) reminds us, that in developing innovative approaches to working with children it is critical to understand and address issues at the personal, micro and macro levels. He refers to a socio-political paradigm of disability which rejects traditional medical models of viewing the child as 'deficient' or the 'problem' as 'within child', and instead views the child as at the centre of a set of 'deficient systems'. These 'deficiencies' at structural and institutional levels in society, serve to reinforce limiting medical models of disability which leads to further social isolation, discrimination and social injustice. Mitchell's ideas about inclusive education and relating it to disabled children in large scale institutions reflects the social, political, economic, cultural and historical contexts that are present at any particular time. Framing the study within an ecological/socio-cultural approach to children's development therefore aligns well with a socio-political paradigm of disability. Shakespeare, (2000:15) writes on this and frames it as the Social Model of Disability:

'People are disabled by society, as well as by their bodies. It is the social and environmental barriers, prejudicial attitudes and other exclusionary processes which often make living with impairment so hard for disabled people and their families. Cultural representations of disability, and professional discourses of welfare dependency, are another way in which people are disabled. This approach, known as the social model, emerged from the campaigns of the

disabled people's movement. It can enable us to look at care debates in a new light. However, it can be applied more broadly to explore the processes of oppression and marginalisation which apply to members of other help-receiving groups'.

The model outlined above has a political focus deriving from the Disabled Peoples Movement and aligns to an extent with both feminism (to be discussed later) and Childhood Studies. It will therefore be considered within the study design, analysis and discussion to come. However, just as Childhood Studies has been criticised for omitting psychology, so the social model has been challenged for similar limitations in its lack of recognition of, what Feminist Disability scholar Carol Thomas (1999) called 'impairment effects' as part of an individual's experiences, commenting that even if disabling barriers are removed, some people will still be excluded from certain activities because of the effect of their impairment. She includes the experience of chronic pain in this (French 2008; Thomas ,1999).

In conclusion, in combining the ecological approach to children's development, Childhood Studies and Disability Studies I emphasise that constructions of childhoods and children's experiences as being part of their wider systems, cultures and ideologies are useful lenses in this study. However, my awareness of tensions between aspects of disciplines and approaches means that the conceptual framing for this research is somewhere in between the various positions outlined above. On the one hand, I see framing issues within the cultural context as significant and I am also wholly committed to the Childhood Studies position that children are able to be active and competent in shaping their own lives. However, I also accept that for many children in large scale institutions they face 'intolerable hardships' (Carter, 2005:38) without the protection of family ties and caring relationships. In this case, these children are 'vulnerable' young children with impairments who need caring, attentive adults to mediate and facilitate their needs and to support and encourage their survival, development, and agency.

1.4.3 Simply Children

I wondered throughout the research process and in writing up whether I should be making specific reference to the additional needs of children with impairments, who depending on their 'impairment label' and the potential 'impairment effect' (Thomas, 1999), may have specific support or enhanced needs. However, this troubled me, as from personal and professional experience, *all children* are unique, and all children have 'different needs' and 'ordinary needs'. I was also troubled by this position because research demonstrates that all children growing up in large scale institutional care are typically 'developmentally harmed' and disabled further as a consequence of the features of institutional life (UNICEF, 2005; UNICEF, 2007; Nelson et al, 2014). I was aware that some of the children in Area A who were included in this study may have entered the institution without impairment and may have acquired impairment as a result of institutional life. Therefore, whilst the study specifically looks at a project which worked with children with impairments, I focus, in my analysis, on the '*ordinary*' needs of *all* children with the justification that all children share such needs if they are to thrive, flourish and develop to their potential.

This position is reflected in Freya Haradsdottir's (2013) chapter, 'Simply Children', about her experience as a child with a physical impairment, when she recounts that; 'when I was little my mother was often asked if she was raising me as a disabled or non- disabled child, which she found quite amusing. 'I am raising a child' she always replied'. I therefore use the term 'children' generally throughout this thesis to assume *all* children and *including* children with impairments. Where I am speaking specifically about issues relating to children with impairments, I will make that clear and will interchangeably use terms 'children with impairments', or 'disabled children' in line with social model thinking. I also chose to use the term 'disabled children' to reflect my own understanding that children are disabled by institutional life (Tobis, 2000, Mulheir, 2012). Cameron (2014:91) notes that 'language matters for our

understanding of disability, because it is through the words we use that our expectations and assumptions are shaped’.

1.4.4 Children’s Rights

Discussions and debates about institutional care for children have continued to focus on the harmful effect of such care on children’s health, well-being and development, but have also, more recently, considered children’s needs with a focus on their human rights in accordance with the United Nation Convention on the Rights of the Child (UNCRC) 1989 (Denor, 2011). This human rights legislation, which all but two countries of the world have ratified, ‘set out universal values and aspirations for children’s development, well-being, protection and participation’ (Papatheodorou, 2012: 5), in place to ensure the survival, development and security of the child (Brooker, 2008). Of particular relevance to this study, article 6 states that,

1. States Parties recognise that every child has the inherent right to life.
2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

and article 23 states that,

1. States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child’s condition and to the circumstances of the parents or others caring for the child’ (UNCRC, 1989).

The Council of Europe ‘Recommendation on Deinstitutionalisation and Community Living of Children with Disabilities’ highlights concerns that the placement of children in institutions as a form of alternative care ‘raises serious concerns as to its

compatibility with the exercise of human rights' (Crin.org, 2018). Likewise, Denor et al (2011:21) state that 'long term residential care has a tendency to overlook or directly violate children's rights'. Discussion is now firmly positioned within a much wider agenda of worldwide and European directives and legislation focused more around a discourse of children as 'rights holders', However, a global human rights agenda is not without its own cultural interpretation issues and can fall into the trap of becoming culturally detached (Jones and Welch, 2018).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has also generated action to improve the quality of life of people with impairments on a global scale (United Nations, 2006). Alongside the United Nations post 2015-2030 Sustainable Development Goals, which includes reference to disability throughout (un.org, 2018) the UNCRPD is calling for huge paradigm shifts in societal attitudes towards people with impairments, including reappraisal of policy and practice by governments, policy makers, researchers, service planners and providers. Member States are committed by international law to the fundamental General Principles underpinning articles such as right to life, education, health and independent living (unpublished Northumbria Law School Report, 2011).

This human rights interest and focus has led to increased emphasis on policy change but this has not led to practice change at the rate expected and hoped for. Whilst there is a drive to close large institutions, to improve life and daily experiences in smaller group homes, to develop foster care arrangements and to develop more inclusive policies and legislation to support parents who are at risk of losing their children to state care (Ismayilova et al 2014; Ivanova and Bogdanov, 2013; UN, 2010), national responses vary (Eurochild, 2014; UNICEF,2005).

The principle of human rights, specifically children's rights, including the rights of children with impairments, is a key driver for this research. It is evident that children living in institutions around the world, without family care and intimate attachments, have impeded potential for healthy and optimal development, something made worse by their comparative invisibility. In large institutions children are at a substantially increased risk from a range of abusive practices including sexual abuse, exploitation, and physical and psychological harm, with disabled children being especially vulnerable to abuse and neglect (Save the Children, 2009; Mulheir, 2012). This leads to further health problems and exacerbation of their 'disability' (Carter, 2005; UNICEF, 2005, 2007). In turn they experience high rates of illness, malnutrition, severe developmental delay, and premature death (United Nations, 2006). According to Nelson et al, (2014), young children and children with impairments living in institutions and without parental care, are some of the most vulnerable children in the world. Children are dependent on others for their human rights to be realised which provides further impetus for intervention (Myers, 1992).

My primary intention in pursuing this study is, as mentioned, to contribute to the global dialogue about the needs and rights of children without parental care. As Arnold (2004) reminds us, countries are legally bound by the UNCRC to honour children's rights, which provide the firm foundation for initiating public dialogue and action on behalf of young children. Furthermore, there is now 'widespread consensus that segregating people with disabilities in long-stay institutions is not an acceptable practice in the 21st century' (USAID, 2013:1) and the confinement of children in this way is now recognised as a violation of their human rights (ibid). Such work is needful as large institution in particular, are often geographically placed away from communities, something which serves to distance the children from both their wider communities and their human rights (Disney, 2013).

My commitment to this subject as a children's rights issue therefore overrides my uncertainties and anxieties about appearing to be pursuing and reinforcing a 'colonialist' and ethnocentric agenda in my approach to the work. Although I am a white British woman, I position myself as a member of a global community which means "that all of us, consciously or not, depend on each other. Whatever we do, or refrain from doing, affects the lives of people who live in places we'll never visit." (Bauman, 1995:287).

In 2010, following accession to the European Union, and with pressure from European partners, the Bulgarian Government declared deinstitutionalisation as a main priority in the childcare field and began to implement its 2010-2020 strategy which prioritised disabled children (Terzia and Araabska, 2017). Of specific bearing to this study is that in 2010 when I began my volunteering, I was aware that the de-institutionalisation strategy was in its formative stages. However, deinstitutionalisation is a long, complex process (USAID, 2013), and with over 200 institutions in Bulgaria at the time, reform was not likely to be a quick solution (Sotiropoulou, & Sotiropoulos, 2007). With this in mind I was concerned about the children in Institution X who, living during that transitional time, and experiencing the 'gap' between the development of a policy and its full realisation (Mitchell, 2005), were susceptible to further isolation and developmental harm.

1.5. Research Aims and Approach

In developing the research aims, I wondered about the role of the Babas in potentially instigating some kind of 'de-institutionalisation' for the children within the institutional context, in effect asking whether the Babas' input could offer protective factors. This resulted in the overall research aim becoming:

- to explore the role of local grandmothers in providing alternative caregiving practices to disabled children, and to examine their potential to contribute to the de-institutionalisation process while the children remain in the institution.

This was broken down into four exploratory research questions:

- Is the impact of institutional care harmful for children? If, so, how?
- What do the Babas do for the children?
- What is the significance of their interactions and caregiving role?
- How are the babas contributing towards the de-institutionalisation of the children, and what, if any, are the implications for policy and practice?

In order to address this focus I wanted to seek the meaning of the Babas' role from the Babas themselves, as well as professionals, NGO stakeholders and volunteers who had worked alongside the Babas with the same children. I therefore employed a qualitative methodology informed primarily by a feminist research approach that embraces and appreciates reflexivity and positionality, whereby the researcher rejects notions of being objective, free from bias and emotionally detached (Hesse-Biber, 2014). The research also takes account of the principles of Disability Studies research and the position of Childhood Studies in relation to children in the research process (Barnes and Mercer, 1997; Mukherji and Albon, 2010).

Semi structured interviews were carried out in Bulgaria and in the UK with Babas and professionals working in Institution X, NGO representatives and volunteers. A rigorous thematic approach to data analysis generated key themes which addressed the research focus. My voice tells the story of this research project and I incorporate my reflections, both on the experience of volunteering and regarding developing the

research. In doing so I take responsibility for the final narrative and enhance the trustworthiness of the research.

1.6 Structure of the thesis

This thesis is organised into seven chapters. The first chapter states the aims and rationale and presents my motivation for undertaking the work. It also outlines the subject area and conceptual starting points. Chapter two critically discusses the literature in this area which provides a context for the study from which to understand the findings. Chapter three describes and justifies the chosen methodology and methods, and explores my position in the work along with ethical considerations. Chapters four, five and six are findings and discussion chapters which build progressively. Chapter seven concludes the work with a consideration of theory, policy, and practice. I also take the opportunity in this chapter to present my final reflections on the study.

Chapter Two

The Developing Child and the Bulgarian Institution

2.1 Introduction

Chapter one provided an overview of the research study, including an introduction to some of the key conceptual themes which have influenced its development, some contextual information about the Baba project, as well as an introduction about myself as the researcher and my motivation for pursuing this study. I introduced some of my diary reflections written during volunteering in Bulgaria and explained how the process of revisiting them helped me to shape and refine the focus of the study. These diary reflections also partly influenced the development of this literature review in helping to identify some initial themes, or foundations. They led me to seek further understanding of the subject area, drawing from my academic knowledge and insight in the disciplines I was familiar with (Sociology, Social Policy, Psychology [child development], Childhood and Feminist Studies), as well as venturing into Disability Studies literature, a fairly new territory for me. Each diary reflection helped me to identify and revisit literature that I was already familiar with as well as helping me to identify 'gaps' (see examples provided- appendix 1).

A key element of this research is concerned with exploring caregiving. As noted by a global review of caregiver-child interactions by the World Health Organisation (WHO, 2004), research and literature focusing on caregiving practices comes from an 'enormous field of study'. Likewise, my concern with Childhood Studies means engaging with the wide range of genres, disciplines and huge field of literature it developed from (Gabriel, 2017; Mills and Mills, 2007).

The subject of this PhD therefore means I draw on disciplines which are eclectic and so this literature review does not neatly align with one fixed field of study. It includes the intersectional examination of literature and research from the field of Early Child

Development (ECD)⁴ to understand how caregiving practices cross culturally contribute to favourable conditions which encourage and support a child's optimal development. I discuss this literature in relation to research around institutional caregiving practices to explore why, whilst offered as an 'alternative to family care', institutional care is so notoriously harmful to children's development. Goffman's concept of the 'total institution' will also be considered to develop further understanding of 'institutionalisation' and 'de-institutionalisation' which are central to an analysis of the significance of the Baba's role. In addition literature from Disability Studies provides a theoretical lens for understanding the experiences of disabled children in family contexts, as well as in institutional care.

The core of the study is framed within an ecological approach to children's development (Bronfenbrenner, 1979; Bronfenbrenner, 1986), which suggests the need to address and understand the Bulgarian context of institutional care. I have therefore also drawn upon a wealth of international reports by organisations such as Save the Children, World Health Organisation (WHO) and UNICEF which are discussed in relation to Bulgaria. Such reports generally lean towards a human rights focus, the impetus for this study, and also add to an understanding of the global context for children's health, well-being and development, family support and alternative sources of care for children without parents.

The content of this chapter has been organised to reflect the approach outlined in the introduction which emphasises the importance of studying children's experiences in the context of their culture, or their 'ecological niche' (McDowell Clark, 2010; Packer, 2017, Super and Harkness, 1986, Harkness and Super, 1994). As noted by Burman, (2008:9) 'children and childhood are constructed, we therefore have to study not only

⁴ ECD is recognised internationally as the period from birth to 8 years (Gabriel, 2017)

the child, but also the context'. I therefore begin the chapter with an introduction to child development theory relevant to this research, including the ecological approach, before going on to explore literature which explains the Bulgarian context and how institutions are harmful to children.

2.2 Child Development

2.2.1 An overview

Child development has been defined as a 'dynamic process of change by which children progress from dependency on caregivers from birth and during infancy towards growing independence into later childhood and beyond' (Bornstein and Putnick, 2012:47). It is a term often used to refer to a child's growth, maturation and emerging skills in a number of different domains including physical, emotional, sensory, social, cognitive and communication and language (Walker et al, 2007) which is typically presented as a continuous and accumulative process (Smidt, 2013). Contemporary writers emphasise the inter-related nature of these domains, highlighting the importance of taking a more holistic approach to studying the developing child (Docherty and Hughes, 2014; Santrock, 2015), something reflected in this study. Myers (1992) summarises child development into five core features arguing that it is; *multi-dimensional* in that there are many aspects of development that need to be considered; *integral* as all dimensions are interrelated and cannot really be considered as 'stand-alone' parts of a child; a *continuous process* as the child is always developing; and *patterned but unique*, thus recognising the individual variations in a child's biological and genetic make-up as well as external factors influencing their development. Bornstein and Lamb (2011) outline four related goals in the study of children's development; *describing* the child in relation to ages and stages, *explaining* how the differences in children's development take place and happen over time, attempting *to make causal predictions* based on what has gone before for the child, and finally, identifying the most *effective intervention* strategies

based on knowledge of child development theory to promote further development and well-being for the child.

Earlier models of child development psychology, or, the 'classic theories' dominated thinking for many years (ibid). Historical accounts of the various descriptions, explanations, predictions and developments in the study of child development are documented very well elsewhere in an abundance of child development texts. To summarise briefly here for the purpose of showcasing the contextual aspects of the ecological approach and establishing its conceptual 'fit' with this study it is useful to understand the three key traditions, as presented by Bornstein and Lamb, (2011) which were most influential and which preceded the ecological and contextual approaches (Bornstein and Lamb, 2011). From the early 1900s maturational (biological) theories dominated thinking which proposed that a child's development 'unfolded' as a result of 'genetically determined sequences of development' (Bornstein and Lamb, 2011; Doherty and Hughes, 2009), therefore associating development with growth. Based on the foundations of this approach, the Child Study Movement of the early twentieth century which was formed in America and in some European countries, carried out many 'scientific' studies which led to the beginnings of 'normative' statements about children's development and the dominant presentation of a 'universal child'.

Almost in direct contrast to this 'within child' focused approach, in the 1950s behaviourism emphasised the role of nurture rather than nature in 'moulding' the child, thus presenting development as a result of the child's learned responses and behaviours. The behaviourist approach, coming from research primarily on animals, is captured by a simple analogy that the child, or the child's *biology* (nature) is the clay, and the *environment* (including the adult) shapes it. Basically implying the child comes to the process from the starting point of nil. The third key tradition referred to

by Bornstein and Lamb (2011), and one which became highly influential in child development circles and in education, is Piaget's 'constructivist' approach which challenged the binary nature of the nature vs nurture divide. This approach presented argument for the consideration of both the endogenous and exogenous factors in children's development, thus presenting the child as active in the development and learning process (Doherty and Hughes, 2014; Smith et al, 2014). Piaget proposed that the child developed as a result of adaptation to their environment, a 'trial and error' approach whereby the child learns by 'experimenting'. Key for Piaget was his view of the child as an active shaper and constructor of their own understandings of the world, based on their own exploration and discovery, and manipulation of objects. This view of the active (not passive) child marked a shift in developmental psychology which informed a shift in educational practices in the UK and other European countries (Sutherland, 1997; Smith et al, 2014). However, whilst Piaget's theories considered the role of, and the relationship between, both nature and nurture he was critiqued as having not paid attention to culture or context (Donaldson, 1986).

Another constructivist approach, but one which stressed the social context of learning developed, stems from the work of Vygotsky (1962, 1978). He viewed the child as an active constructor of knowledge but placed great emphasis on the direct intervention of others, arguing that the child acquires the 'tools' of thinking and learning as a result of social interactions with others and in a range of social settings (Woodhead et al, 1998). He emphasised the role of others in supporting the child beyond their 'actual' level of development. Vygotsky referred to this area between the 'actual' and 'potential' level of development as the 'zone of proximal development'. Building on this, Bruner (1960) used the metaphor of 'scaffolding' to explain how 'more able' peers or adults use effective strategies to support the child, with the more contingent responses giving more success (Daniels, 2009; Woodhead et al, 1998; Flear, 2006).

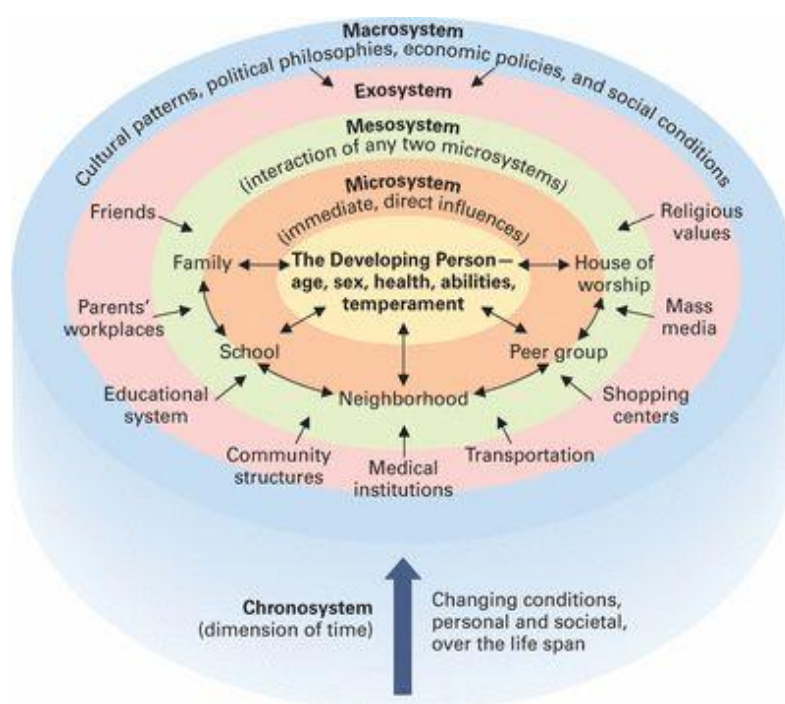
The concept of culture and context that informs the child development approach framing this research emerged primarily in the work of Urie Bronfenbrenner who, in his 1979 text 'The Ecology of Human Development: Experiments by Nature and Design' highlighted the lack of consideration given to the 'context' evident in dominant child development (psychological) models of the time. In contrast, he emphasised the cultural and contextual aspects of a child's development, specifically the relationship and interconnectedness between the developing child (bio) and the 'systems' of the culture and society they belong to (ecological). His 'bio-ecological' model is most typically presented visually as a series of concentric circles representing different 'layers of influence' around the child. He likened the world of the child to a 'set of Russian dolls' (Bronfenbrenner 1979:22) with the child at the very centre, surrounded by a set of wider systems radiating out from the child that both directly and indirectly influence their experiences and development. In this model,

'the emphasis is less on traditional psychological processes such as perception and motivation, and more on the ways in which a person's interactions with their environment, and the content of that environment, impact upon those psychological processes'
(Robson, 2012:46).

This model, also referred to as a systems model emphasises the complexities of interrelationships between the developing child and their environments, and the interactional nature of the different 'layers of influence' (Robson, 2012). The innermost circle, the 'microsystem' represents the child's most immediate everyday context and experiences which in typical family contexts cross-culturally would include primary caregivers and other immediate interactions and settings involving the child. The 'mesosystem' represents the links between the family, the home and other proximal institutions such as the local clinic, toddler group or play group. The 'exo system' includes factors which are more distant from the child but can still indirectly affect them, for example community networks, parent's workplace policies and patterns of

work. The macro system represents the wider structures around the child which influence all aspects of the microsystem, for example, the legislative and policy frameworks, political agendas, education, childcare and welfare policies, values and dominant ideologies of a society including beliefs about children, disability and family responsibilities (Bronfenbrenner, 1979). Critics of this early model of Bronfenbrenner's approach (including Bronfenbrenner himself) were quick to point out its flaws, as a model of 'context without development', placing too much emphasis on the context and not enough on the nature of the interactions that the child was also part of (Tudge et al, 2009). In response, Bronfenbrenner developed his ideas into a more complex model consisting of Person, Process, Context, Time (PPCT Model). This model took 'time' into account in an additional layer entitled the chronosystem (see fig 1).

Fig 1 Bronfenbrenner's ecological systems model (Source: Google images)



This later model with the additions of the chronosystem is of particular relevance to this PhD study because, as highlighted in the introduction, the children in this study are caught up in a particular period of time which has affected both their admission to the institution in the first place, their daily lives, and their experience of the transitional

de-institutionalisation period. Addressing the child, as well as the context, the emphasis on development in this PPCT model is through the 'proximal processes'. These are the enduring forms of increasingly complex interactions between the child, others, objects and symbols in the immediate environment (ibid). Tudge et al (2009: 200) explained these proximal processes as 'the types of things that regularly go on in the lives of developing individuals'. The use of the term proximal meaning 'near' and implying closeness as opposed to 'distal processes'.

In the model, 'transition' appears in all layers of influence and it is well documented that transitional times in children's lives pose opportunities for positive change, but also pose threats which can leave children vulnerable (Vogler, 2008; Brooker, 2008; Fabian, 2009). Using theory from anthropology and 'rites of passage', it has been demonstrated that transitions place children in a 'liminal state', which is the period between a separation and a re-incorporation. This state has been referred to by Turner (1969: 95) (cited in Vogler, 2008) as "betwixt and between", and could be meaningful in terms of de-institutionalisation. Writing about emotion socialisation in Russian orphanages, Stryker (2012; 89) recognises the liminality of orphanage children following the collapse of communism. Caught up in that 'state of being between caregivers as well as between economic and political systems' they will 'never be considered completely Russian and thus not absorbed cleanly into economic and social systems after emancipating from the orphanages at 18'.

The ecological approach framing this PhD also draws upon other similar contextualist positions, or socio-cultural approaches (Rogoff, 1990; Harkness and Super, 1994). Building on Vygotskian perspectives, the role of culture is prominent as it informs the child's 'developmental niche'. This is a term used by Harkness and Super (1994) to refer to the three main elements within children's immediate environments which play a role in their development. These are;

- the physical and social settings of the child - this refers primarily to the child's family and the ways in which daily and social life are organised
- the culturally regulated customs and practices - which relate to how children are raised in different cultures with attention paid to how caregivers mediate these embedded customs and beliefs into the children's experiences.
- the beliefs or ethno theories of the parents, or their psychological characteristics. This includes the goals and priorities of the parents for their children, together with their views on how best their children can achieve these goals (Bornstein and Lamb, 2011; Smidt 2013; Vogler et al, 2008).

The child sits at the centre of the model and is viewed as actively contributing to their developmental niches through their own expectations and through their interaction with their caregivers (Super and Harkness, 1986). Further, taking a socio- cultural perspective, Rogoff (1990) emphasises the interaction of the systems around the child as forming the 'crucible *for* development' rather than 'influence *on* development'. She stresses that 'to fail to consider a behaviour in its cultural- historical context is to risk misinterpreting its meaning, and hence its overall psychological significance for the people involved' (Bornstein and Lamb, 2011:76). She uses the concept of 'guided participation' to accentuate the interactive nature of the level of adults and peers,

'guiding children towards full participation in culturally valued activities While the process of guided participation is universal, it differs according to the degree of communication between children and their caregivers, as well as in the skills expected from mature community members' (Rogoff, 1990:190).

Of relevance to this PhD study is that Rogoff stresses the constant engagement in absorbing their culture not only through active participation, but also during times when they appear passive (Rogoff, 1990). It is important to note that contextualist theories are not focussed primarily on the context of the child as the explanation for a

child's development. However, they do attempt to understand and shed light on the complex and indivisible links between a child and their environment (Green and Hogan, 2006:104). To summarise understandings of child development, as stated by Music (2011:24),

‘A human life develops from the delicate interplay of nature and nurture, the meeting of a bundle of inherited potentials and the cultural, social and personal influences of the adults in an infant's life’.

Having outlined briefly the three key child development traditions of maturationist, behaviourist and (individual) constructivist which preceded the development of the socio ecological approach, it is important to note that attachment theory (Bowlby, 1969; Ainsworth, 1978) also took hold from the 1960's which encouraged interest in the affective aspects of child development, specifically the importance of one significant relationship (Bowlby, 1969; Ainsworth, 1978). The concept of 'attachment' has become embedded into child development discourses since then, and has been a significant feature in policy debates relating to early childhood globally (Allen, 2011) although not without critique for numerous reasons (Burman, 2008; Birns, 1999). It is particularly significant to this study as it is the lack of the intimate and close relationship with a caregiver that is cited as most damaging to children in large institutional settings and where children have experienced abuse and neglect (Nelson et al, 2014; Mulheir, 2011; Dozier et al, 2012).

2.2.2 Understanding the 'microsystem' and caregiving practices.

In the absence of family care, the institution is the context of the earliest experiences, or the microsystem, for the children in this study. This section will continue to explore child development literature and perspectives which identify the needs of young children in order for them to develop and thrive, something which will be used later to

analyse the potential of the institution as the main source of caregiving and whether it can be a healthy and fulfilling context for child development.

I established in the previous section that the developing child is not simply an 'empty vessel' waiting to be filled with knowledge (Parker-Rees, 2010), nor is the child as passive as has been suggested by early behaviourist theorists, such as Pavlov, Thorndike and Skinner, who proposed that children could be 'conditioned' in a 'stimulus/response/reward bubble devoid of any cognitive input to the child' (Parker-Rees, 2010:15). It is now widely acknowledged that child development is not simply a process whereby the child is 'manipulated, moulded and managed' through expected levels of development, 'shaped' to behave in particular ways (Docherty and Hughes 2014), but that the child is an active agent in the process of development and is indeed a competent and skilled learner from birth (David et al, 2003). The sophisticated tasks for a new baby as they engage with the complexities of making sense of the social and physical world, are highlighted by Smidt (2013) who captures the many facets of the young child's developing skills. She describes the child as 'a meaning maker, a 'creative thinker', a 'symbol user and symbol weaver, a role maker'. Likewise, Robson (2012:1) describes young children as 'active, persistent thinkers, driven by a desire to make sense and meaning in their lives, to connect what they know and understand to what they do not yet understand'.

This development takes place within the context of the 'microsystem', which Bronfenbrenner defined as 'a pattern of activities, roles and interpersonal relations experienced by the developing person in a given setting with particular material and physical characteristics' (1979:22). He further describes the setting as 'a place where people can readily engage in face to face interaction', identifying the critical importance of dyadic relations which serve as the 'basic building block' of the

microsystem. As previously noted, it is these dyadic relationships that encourage the child's development and enable a progressive expansion of the developing child's world. The microsystem represents the child's own 'little world', placing much emphasis on the reciprocity in relationships between the child and their caregiver (Tudge et al, 2009)

Close examination of the microsystem focuses on the child's experiences in a family, with the acknowledgement that the family is widely accepted, in various guises, as the primary experience of being cared for, for most children. The family is therefore the environment in which children first form attachments, learn about others, learn to communicate and become aware of the values, practices and beliefs of the culture they have been born into (Doherty and Hughes, 2009). This immediate environment of familiar routines, caregiving practices and relationships is the child's 'core entity for learning about the world' offering them a 'reference point' from which to make sense of the wider world which they gradually become a part of (Swick and Williams, 2006:372). For most children, the microsystem consists of their most intimate family members, their family home and may also extend to close friends, family relatives and the local community.

Of course, this space can vary from child to child across cultures and countries, in some cases providing a happy, safe and nurturing experience for the child, and in others 'becoming a haunting set of memories' (Swick and Williams, 2006:372). Microsystems characterised by emotional warmth, nurture and encouragement provide children with opportunities to develop positive perceptions of themselves and others, and from this foundation of trust they can increasingly explore the wider environment with interest and with confidence. Such microsystems can also provide resilience in adversity, for example for children and families experiencing

unemployment, poverty, discrimination and other social pressures. Swick and Williams (2006) note that any work with families under stress should focus on the development of supportive microsystems.

For disabled children without parental care who have grown up in institutions, it can be assumed that their microsystem is not a warm, safe and stimulating space, and is therefore not conducive to their optimal wellbeing and positive development. As this chapter develops to explore the impact of institutional care, it considers whether the institution is an effective microsystem, raising questions as to whether institutions can be developmentally appropriate environments for young children. Of relevance to this study, and from a Disability Studies and Childhood Studies perspective, is that the way the child, and 'childhood', is perceived and constructed in the wider macro systems connects with the activities and relationships in the microsystem (Robson, 2012; Leonard, 2016). Regardless of whether the different perspectives and early theories outlined earlier in the chapter prioritise the role of genetic inheritance over environmental factors, vice versa, or somewhere in between, there are three key themes consistently emerging from the child development literature of relevance to this study. These are;

- the importance of responsive caregiving practices which promote primary attachments during the child's earliest days, months and years,
- the need for an enabling environment which provides the child with opportunities for active exploration of the world around them,
- the widespread recognition and understanding that children are born into communities and complex cultural worlds which play a key role in shaping the child's experiences and development.

Having introduced some child development perspectives which are useful as a starting point, I now move on to a discussion of institutions and institutional care in Bulgaria. Child development will be revisited later in the chapter in relation to developing an understanding of why institutional care is harmful to children.

2.3 Conceptualising institutionalisation and de-institutionalisation

The following section will define and explore the key aspects of institutions such as orphanages. In doing so it will critically refer in particular to the classic work of Erving Goffman.

2.3.1 The ‘total institution’

Drawing from the field of Sociology, Goffman’s (1961) concept of the ‘total institution’ is a highly useful starting point in providing a definition for the terms; institutions, institutionalisation and de-institutionalisation. An overview of the ‘total institution’ at this point in the thesis also provides a theoretical and conceptual framework which adds to the understanding of institutional life for the children in Area A. As a symbolic interactionist, Goffman was concerned with the everyday life, interactions and meanings constructed by the individuals in large institutions. In order to understand what life was like for the ‘inmates’, he carried out covert ethnographic research of life in a mental hospital, written up in classic text, ‘Asylums’ (1961). His observations led him to use the term ‘total institution’ to describe the ‘encompassing tendencies’ of every institution characterised by their isolation from the outside world, both physically and socially. Goffman likened the mental institution and the interactions within it, to prisons, concentration camps, monasteries, orphanages, and military organisations. He argued that total institutions develop their own rituals, rules and roles which function to best meet the needs of the institution and in doing so, serve to oppress

and control the 'inmates' (Barnes et al 1999; Green, 2009; Goble, 2008; Hinshelwood, 2001).

Goffman (1961) distinguished between five types of total institution, these being places that are:

1. designed to care for people considered both harmless and incapable,
2. established to care for people felt to be incapable of looking after themselves but also a threat to the community,
3. organised to protect the community against what are felt to be intentional dangers,
4. established to better pursue some work tasks,
5. designed as retreats from the world

Goffman also recognised that all institutions exhibit some of the elements that define a total institution. He argued that the main point of the 'total institution' is that the many human needs of the entire block of people are under bureaucratic control, summarising it as

'a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life' (Goffman, 1961:xv).

Following Goffman, it would appear that, at first glance, an orphanage such as Institution X would fit into category 1, as they 'contain' those children at risk due to lack of capacity, who could therefore potentially be considered as both vulnerable and harmless. However, this seemingly benign categorisation can be re-evaluated in the light of other aspects of the 'total institution', particularly the way that the individual needs of the residents are not acknowledged. The 'total institution' manages the 'block' needs of residents in an impersonal and oppressive manner, whereby daily life involves the enforcement of a series of punitive regimes which serve to create a

barrier between the resident and the wider world. Such practices involve a series of 'mortification processes' that strip the inmate of any remnants of their former self and identity (Green, 2009). Goffman uses examples of individuals having their heads shaved, and being given 'institutional clothing' which removes individuality from the person; referring to this process as a 'curtailment of self' (Barnes et al, 1999, Mouzelis, 1971). These systematic and continuous 'mortification processes' make it easier for staff to manage large groups. As stated by Mouzelis (1971:9), 'degraded and demoralised human beings are more pliant and easier to administer than those with a high degree of self-autonomy and initiative'.

Further work on the concept of the 'total institutions' focused on specific case studies, many of which offer suggestive conclusions for this research. For example, a Canadian study by Malcradia (2005) used Goffman's concept to frame the experiences of survivors of an institution for adults with learning difficulties during the 1980s. Malcradia argues that practices which operate as mechanisms of social control through stripping residents of their former identities, also function to strip individuals of their humanity. This, in turn 'enabled' the staff to objectify the residents leading to abusive practices. She notes that in a total institution:

'Dehumanisation can be an end in itself, by making the daily work of cleaning, bathing, feeding, housing and 'training' inmates simpler for staff, who are no longer compelled to observe the decencies demanded by human inmates... When the daily chores attendant with 'care' are constructed in such a way as to be aimed toward 'non-humans', the niceties of privacy, respect and tenderness come to be seen as superfluous.' (Malcradia, 2005)

Similarly, a published PhD study by Penglase (2005) used Goffman's concept of the 'total institution' to analyse the experiences in Catholic children's homes in Australia during the 1960s. She exposed abusive practices largely stemming from the 'secrecy'

and isolation of the homes, which completely reflected the 'total institution' and which caused lasting harm to the 'survivors'.

In an unpublished autobiographical account of his working life as a Social Worker in both the UK and abroad, Professor David Brandon drawing on his extensive professional experience of institutional life, captured the essence of the totalising institution:

'Visiting these vast places- prisons, hospitals, residential schools...over many years, gradually corrodes the sensitive layers. Their huge scale is never the liberation of Alpine ranges...In institutions you feel diminished, tired and listless, not expanded. There is a loss of authentic sense, feeling of a tiny useless marble rolling around a huge stadium. They are dessicated human warehouses, where socially excluded people get deep frozen, no human distress is dealt with, just drowned in soporific drugs. All these bleak places are all so unnervingly similar, exuding an intricate culture of secrecy, high walls and barred windows hard to see from, uniformed ways of behaving, rigidly set meal times, sparse choices' (Brandon, unpublished, 1998: page 17)

In a British context Potts and Fido (1991) chronicled the lives of people with learning difficulties in a 'mental deficiency' institution (8 men and 9 women with an average of 47 years in an institution). This research can be seen as relating to Goffman's concept, but also to this study, as the reasons that they were placed there reflected a wide range of circumstances, as is the case in Institution X, and what might be seen as problematic dismissals of their agency and individuality through institutionalisation and their treatment therein. The reasons given for their being placed there were: poverty, death of parents, not getting up for work, the removal of their children and having to teach themselves to read and write. Within the institution punishments included cold baths (so called heroic treatments). When Potts and Fido wrote their account, these individuals were amongst a much smaller number of hospitalised 'inmates', given that after 1954 concerns about social well-being, promises of rehabilitation in the community, increased tolerance in communities and new patient

management drugs (Scull, 2011) meant there was a decline in numbers. All the same, their narratives are indicative of the 'total institution'.

Finally, research suggests that staff are also typically 'institutionalised' by working within the confines of the 'system' of the total institution. This too has implications for this thesis, particularly as staff in large scale orphanages are reported as working long hours with few breaks, often with ratios of one member of staff to over 20 children. Conditions in institutions are 'bleak' and the work is, typical of childcare, very poorly paid (Dozier et al, 2012).

2.3.2 Stigma

Goffman's (1963) concept of stigma is also central to any discussion of those in institutional care. According to Goffman stigma refers to the negative social response to certain features of an individual ('imperfections, 'marks' or blemishes') or their circumstances which stigmatise the individual and 'spoils' their social identity. Goffman states that, 'By definition, of course, we believe the person with a stigma is not quite human' (Goffman, 1963: 15). The key feature in this process is negative social stereotyping and de-valuing. The devalued person or group becomes discredited and perceived by the valued group as deviant which allows 'dehumanisation' (Goffman, 1963:5) and othering. An example of how this can work was seen when members of Rosenhan's (1973) research team got themselves admitted to various psychiatric hospitals. They were instructed to say they had heard a voice and elicit no other symptoms. All were, nonetheless, diagnosed as having schizophrenia. Rosenhan describes how the behaviour of these pseudo-patients was interpreted and reframed as continuing evidence of their abnormality. This classic study clearly highlights the all-encompassing effects of a label, of stigma, upon individuals.

To return to Goffman's 'total institution', his second category, that of being seen as potential threat to others, relates to stigma and sheds light on why some of the children in Institution X have been placed there. He referred to category 2, large scale institutions as 'dumping grounds' or the 'storage dump' for all those perceived by wider society as 'unclean' and therefore stigmatised. He also notes that one of the functions of the 'total institution' is to protect the wider community from an assumed 'pollution' from those individuals.

This relates to work in Disability Studies highlighting the effects of stigma on people with impairments (Davis, 1997), and more recent work specifically about the experiences of disabled children (Lalvani, 2015; Beazley and Williams, 2014). McLaughlin and Goodley (2008) have used the terms 'medical othering' and 'societal othering' to explain how both the medical diagnosis and the societal response to this serve in the 'unmaking' of the child. They note the significant role of parents and other family members in challenging this process. It is recognised that disabled children are some of the most stigmatised and excluded in the world, often spending their lives on the margins of society, away from their families. In communities where negative associations of shame and fear prevail for children with impairments, even when families do manage to keep their disabled children at home they are frequently kept hidden away from wider public and social arenas (WHO, 2012). Writing about Eastern European post-communist societies, Katsui, (2014) notes that in these societies, where impairment is stigmatised, there is a danger that families and individuals come to believe that impairment is an individual 'problem' to be kept hidden within the family, and 'dealt with' privately. This exclusion from society then reinforces and normalises prejudice (Katsui, 2014).

Having examined the wider concept of the 'total institution' and how it relates to stigma, the chapter now moves on to examine how this concept is specifically reflected and understood in relation to the institutional care of children.

2.3.3 Institutional care of children

Reports and discussions of institutional care for children have demonstrated difficulties in definitions because what constitutes institutional care inevitably varies from one country to another and is particular to a range of different cultural heritages and traditions (Ivanova and Bogdanov, 2012). For example, Browne (2009) uses size as a defining characteristic, noting that 'an institution or residential care home for children is defined as a group living arrangement for more than ten children, without parents or surrogate parents, in which care is provided by a much smaller number of paid adult carers' (2009:1). In contrast, Ivanova and Bogdanov (2012) propose that children being placed there for an indefinite amount of time and having little contact with their parents, families and the wider community is key. National variations are indicated in the way that across CEE/CIS countries, and, pertaining to this research, Bulgaria, many children enter institutions at birth and have little or no contact with their families, despite ongoing recognition that most of these children are not actually 'orphans' (Browne, 2009).

Scale and duration, then, are also potentially indicative of institutionalisation rather than a definition of institutions. For example, Muhleir (2012) highlights that there is a difference between 'residential care' and 'institutionalisation', pointing out that the former, in small group homes with well qualified staff can often be an effective alternative to family based care for some children with complex impairments. This suggests that it is more useful to look at the features that typify institutional care, given the global consensus on what aspects are problematic, something arrived at in many reports and research projects. Thus, 'institutional culture', when trying to define

institutions is more helpful than physical features such as size of buildings, numbers of children and geographical location (ibid).

An interrogation of what is meant by institutionalisation and de-institutionalisation is critical to understanding the situation of the children in Institution X and an analysis of the Babas role. To do this, the thesis adopts the approach taken by the Common European Guidelines on the Transition from Institutional to Community-based Care which defines institutional care by focussing on the institutional culture and children's lived experiences of it. Evidently drawing on Goffman's concept of the total institution they define an institution as:

'any residential care where:

- Residents are isolated from the broader community and/or compelled to live together.
- Residents have insufficient control over their lives and the decisions that affect them.
- The requirements of the organization tend to take precedence over the residents' individualized needs.' (European Expert Group, 2012:25).

The term 'institutionalisation' is also used to show recognition that whilst these identified features are usually typical of large scale institutional facilities, the harmful features of institutional culture can also be found in smaller scale residential facilities for children, particularly those with disabilities. For example, WHO (2010) reports that even when living in their own homes, or with foster families or in small group homes, disabled children experience rejection from their local communities and have limited access to a range of opportunities. They state that,

'These children can be just as isolated "in the community" as in large-scale institutions. The proposal has...been made to broaden the definition of institutionalization to refer to the overall phenomenon in

which an individual with a disability loses control over his or her own life' (WHO, 2010:10).

For this Phd study a definition of *de-institutionalisation* is also useful. De-institutionalisation as a term is contested, but fundamentally it concerns the removal of children from large institutions to small group homes and this is typically seen as inherently good practice. In Bulgaria, it is used to describe a set of conditions/processes which involve the removal of children from large institutions to be reunited with their families or placed with foster families, adoptive families or in small group homes. It also includes the development of policies and practices to support families experiencing difficulties, so that they can be encouraged to keep their children, as well as promoting changes in public attitudes towards certain minority groups (Terziev and Arabaska, 2016, 2017). In particular the Roma population, and children and adults with impairments, are significantly over-represented in institutions throughout Europe (European Roma Rights Centre, 2011; UNICEF, 2005, 2007; WHO, 2010). In a report by USAID (2013:2), de-institutionalisation was defined very simply as 'the process of managing the transition from institutional care to community living'. This broad definition is reflected in the wording and targets of Bulgaria's de-institutionalisation strategy, as follows;

'De-institutionalisation is the process of replacing institutional care for children with care in a family or a close family environment to the community but not limited to removal of children from institutions. This is a process of prevention of placing children in institutions, creating new opportunities for children and families to receive support in the community and takes place on many levels:

- work with families and professionals on prevention of child abandonment and institutionalization of children in order to reduce and gradually stop the entry of children to institutions and to support the reintegration of children in their native families;

- reform and work in the social assistance system to implement programs for social support and protection in support of the home and extended family for the prevention of child abandonment and child care in a family environment;
- creation of alternative forms of service and care to enable removal of children from institutions and prevent their placement;
- promote the development of adoption and foster care, focusing on the development of services for children 0-3 years' (Terziev and Arabska, 2016:288).

The wording of Bulgaria's strategy is limited, as it focuses on macro changes and neglects the microsystem of the child currently experiencing institutional life. So, for the purposes of this study, especially in developing a framework for data analysis, the definitions referring to 'institutional culture' and the damaging features of institutional care will be used (European Expert Group, 2012). In this way, a definition of de-institutionalisation can be developed to be put into action, one that reflects features of caregiving practices in direct contrast to the features of the total institution. For example, one can revisit and reword the definition provided by the European Expert group (offered on pg 44 of this thesis), to incorporate caregiving practices whereby:

- Residents are included in the broader community and/or not compelled to live together.
- Residents have sufficient control over their lives and the decisions that affect them.
- The requirements of the residents' individualised needs take precedence over the organisational needs.⁵

⁵ Underlining my own- to emphasise my own changes to the wording of the practices.

Such a definition, which focuses on the culture of life within an alternative care environment for children, acknowledges that Goffman's characteristics of a total institution are not confined to the large scale institutions. Sinson's (1994) research of 12 small group homes in the UK for people with learning difficulties found that the characteristics of large institutions were also evident in small group homes, something she referred to as 'micro- institutionalisation'. It was found that whilst small group homes had markedly improved conditions in comparison to the large institutions, the emerging picture was one that mirrored the characteristics of large institutions. Service users remained isolated from society, as well as having "few opportunities to develop relationships beyond the 'service world', and there remained a persistent divide between the 'service user world' and the 'staff world'" (Goble, 2008:47)

2.4 Bulgarian Context

In line with ecological and socio-cultural approaches, and taking into account Bronfenbrenner's conviction that 'public policy has the power to affect the well- being and development of human beings by determining the conditions of their lives' (Bronfenbrenner, 1979: preface), the wider social, economic, political historical and cultural contexts for institutional care in Bulgaria will now be discussed. This will contribute to an understanding of why the 'large scale institution' model of institutional care as a preference to family based care has been dominant for disabled children in Bulgaria without parental care.

2.4.1 Bulgaria

As stated by Vygotsky (1978), 'a child's development cannot be understood unless we examine the external social world in which that individual lives' (cited in Harvard 1998:39). In a recent 'self-reporting' survey on life satisfaction and 'happiness', Bulgaria was reported as the unhappiest country in the EU (Euronews). This positioning might be a consequence of the period of political and economic instability

Bulgaria has experienced since its transition from socialism and a highly centralised planned economy to a free market economy in 1989, as this has resulted in a long period of poverty and unemployment. Bulgaria is reported as having the lowest GDP in Europe and in 2013 was listed as having the lowest annual salary in the EU (Euronews). The country saw rapid growth 2004-2008, but was hard hit by the economic crisis (World Bank).

Bulgaria's education system shows poor outcomes for children and the share of the population living in poverty remains high. The lack of job opportunities encourages younger members of the population to leave the country, which has accelerated the aging and shrinking of Bulgaria's population: Bulgaria has become the third oldest country in Europe and between 2000 and 2013 its population declined by close to a million (World Bank). It is also worth noting that, in relation to the Babas, in 2015 almost a fifth of the Bulgarian population were over 65, the highest number in the EU. Across Europe, statistics demonstrate that members of the population aged 65 years and over are more vulnerable to persistent poverty than other age groups, (Office for National Statistics, no date) with women being recognised as more vulnerable to poverty than men (EU Publications, 2015).

Finally, the 'Key Data on Early Childhood Education and Care in Europe' (European Commission, 2014) figures on income and living conditions, lists Bulgaria as one of the 5 poorest countries in Europe. In particular, these figures show that 51.4% (one in every two) children under the age of 6 years are at risk of poverty and social exclusion. The average across Europe is one in four. The proportion of Bulgarian families living in jobless households with children under the age of 6 years is also high, with an average of 16.7%, whilst the average across Europe is over 5% lower at 11.2%.

2.4.2 Bulgaria's use of institutional care

Informed by a stream of research findings from the 1940s onwards highlighting the negative impact of the 'batch rearing' of children globally political and public support has gained momentum for the de-institutionalisation of children (Dozier, 2012). However, whilst other European countries have moved ahead with de-institutionalisation strategies Bulgaria and other CEE/CIS countries have lagged behind (Sotiropoulou and Sotiropoulou, 2007; Walker, 2011). This section will highlight some of the reasons for this. The difficulties in defining institutional care, mentioned above, mean that attempts to produce and interpret statistics to assess its use are also problematic (Browne, 2009; UNICEF, 2007). However, even taking this into account, Bulgaria and other CEE/CIS countries clearly have a history of much higher rates of placing children into institutions, with especially high rates for babies, younger children, and children with impairments (UNICEF, 2005).

Complex reasons linked to Bulgaria's political and economic history have been proposed to explain this, most notably the influence of Soviet Communist ideology, which dominated the country's political systems for over 40 years. This is suggested by the work of Markova et al (2008) who chart the rise of institutional care for children since 1938 (pre-communist rule) when Bulgaria was reported as having only 11 institutions for young children. The number increased dramatically during the communist period to 85 institutions in 1960, reaching 133 institutions by 1968. This increase could be seen as reflecting soviet familial ideology which proposed the 'state' as a better parent of children, an ideology which also aligned with the communist approach which welcomed women as equals in the workforce (ibid).

However, whilst the rise in admissions was steep during the communist period, the increase was not confined to those years, which suggests other factors are at play. In

fact, some recent studies have highlighted further increases in use of institutional care since the period of transition from communism in 1989. In 2000, for instance, according to a study by Mihailar, Harizanara and Bogdanova (cited in Markova, 2008), figures suggested that there were 35,000 children living in 285 institutions in Bulgaria. In 2005, a UNICEF report 'Children and Disability in Transition in CEE/CIS and Baltic States', presented research findings from 3 different studies across the 27 countries which make up the CEE/CIS region and listed Bulgaria as one of the top 4 countries for use of institutional care. Admissions of young children and children with impairments are high across Central Eastern European countries (UNICEF 2005), and figures reported in 2010 suggested that the rates of children in institutional care in CEE/CIS countries is 'the highest in the world' (UNICEF, 2010). Bulgaria stood out as having the highest rates of admissions in Europe to large institutions for young children (from birth to 3) and children with impairments (ibid). In addition to high numbers, with regard to institutional care in CEE/CIS countries, Bilson and Larkin (2013) note that the quality of the standards of care practices are considerably lower than in the rest of Europe, with conditions noted as much poorer for children with impairments (Bilson and Larkins, 2013).

2.4.3 Understanding high admission rates

An examination and understanding of the reasons for Bulgaria's high rates of admissions of children to institutions demonstrates the ecological niche's relationship to the developing child and their 'microsystem'. This is key in understanding the role of the Baba in contributing towards de-institutionalisation of the children. Many reasons have been proposed for the country's overuse of residential care in large scale institutions, all of which contest the use of the term 'orphanage', as most of the children placed in these institutions have at least one living parent, with the actual percentage reported as being 'orphans' as low as 2-5% (Carter, 2005). Indeed, a report in 2009 suggested discontinuation of the term 'orphanage' altogether arguing

that its usage reinforces and perpetuates stereotypes about the need for institutions (cited in Dozier et al, 2012:16).

The EveryChild study by Carter (2005) found that the reasons for admission were described as social (43.5%), poverty (39.5%), child abandonment (6.5%), disability of child (2.4%), illness of child (7.3%). These figures suggest an inaccurate picture because it refers solely to 'reasons for admission'. Eurochild (2005), for instance, argues that institutional life is such a harmful environment for children, especially young children, that they develop both impairment and disability as a consequence of it. This was confirmed by orphanage director Tobis's study (2000:57) which explained that 'infants arrive healthy and leave disabled'. It has been reported that Bulgaria had the highest rates of babies / infants in institutional care, with 49% of institutionalised children aged between 0-3 years (Eurochild, 2014). This could lead to many more children with impairments in the future due to the impact of the institutional care. The same reported cited poverty and disability as the two main reasons for children entering institutions in Bulgaria. Despite the issues around statistical accuracy, existing research presents data which shows that children with disabilities are significantly over-represented in institutional care globally, including CEE/CIS countries (UNICEF, 2005; Mulheir, 2012).

The cultural dominance of institutional care for children in Bulgaria is linked to the country's history, especially though the influence of post-world war two communist Russian policies. Bilson (2009) notes that the approach of using large scale institutional care to safeguard children in CEE/CIS countries does not stem from protectionist views. The preference for institutional care for children, originates largely in a soviet ideological stance on 'the family' which sought to liberate women from the confines of their domestic positions within the home and to promote their status as

equals to men in the workplace. A dominant discourse existed which presented state childcare as the best place for children to be reared (Markova et al, 2008).

This ideology pre-dates world war two. The Bolsheviks, for instance, had a firm stance on raising children. The family was portrayed as a 'wholly bourgeois institution' and at least until the 1930s, the official communist stance was that the family, as a typical domestic arrangement, would die out (Creuziger 1996, cited in Carter, 2005). For example, in the first Soviet Code on the Marriage in 1918, it was stated that,

'Our state institutions of guardianship... must show parents that social care of children gives far better results than the private, individual, inexpert and irrational care by individual parents who are 'loving' but in the matter of bringing up children, ignorant'. ..During the same year, the wife of the leader declared that, Children, like soft wax, are malleable, and should become good communists. We must rescue [them] from the nefarious influence of family life... we must nationalise them. From the earliest days of their little lives, they must find themselves under the beneficent influence of the Children's Gardens and the Communist Schools. They will learn the ABC of Communism, and later on become true Communists. To oblige the mother to give her child to us, to the Soviet state, that is our task

(cited in Carter, 2015:6).

That this cultural view continued to have an impact across CEE/CIS countries is clear when Nelson et al (2014:18) note that in the early stages of their project (Bucharest Early Intervention Project with Romanian Orphans), they were informed by some Romanians that 'their project was unnecessary, because the state did a better job of raising children than did families, and children who were abandoned to institutions were by default 'defective' children'. This history indicates the process of cultural accumulation around institutional childcare, for as Bornstein stated, 'culture is the residue in the present of past human activity in which human beings have transformed nature to suit their own ends and passed the accumulative artefacts down to succeeding generations in the form of tools, rituals, beliefs and ways of connecting

with the world' (Bornstein in Rogoff, 2003:76). In Vygotskian terms then, and in relation to child development, the institution can be viewed as a cultural artefact.

Another significant impact of the Soviet legacy on childcare practices in Bulgaria is the societal tradition of 'defectology' which has contributed to social stigma around disability, leading to children with impairments being assigned to isolated 'special' institutions that fail to provide adequate care and stimulation (Aubrey, 2012:54). The term 'defectology' has no straightforward interpretation in the English language, and as it is literally translated as the 'study of defects' (Gindis, 1995, 1999), it does not sit comfortably within a Disability Studies arena.

The term defectology has been used in Russia for over a century to refer to the study of the children with impairments and the methods used to assess and diagnose their 'condition', which is then used to plan their educational provision and their upbringing (Gindis, 1995, 1999). The ideological underpinning of this approach stems from communist Russia and led to the separation of any person with 'problems' and/or 'defects' from the rest of the population. The aim of this segregating practice was to reflect the flawless and 'problem free' society envisioned by communism. Interestingly, the concept was engaged with by Vygotsky in the 1920s. He concluded that it was not the child's impairment which disabled them, rather they were disabled by the environment around them (Daniels, 2009). This almost presents Vygotsky as an early 'social model' thinker, however, his educational philosophy to address the limitations of mainstream education at the time was to provide 'special schools' specifically designed to 'enable' the child's learning away from others. Segregation has never been part of a social model approach. Despite Vygotsky's seemingly good pedagogical intentions, the 'science' of defectology developed into culturally accepted and embedded practice whereby very young babies and children were misdiagnosed and labelled according to seriously limited and rigidly applied defectology principles.

Such fervent use and application of the 'defectology' approach led to the disproportionate over-representation of children with impairments in institutions and 'boarding schools', where they experienced isolation from their families, harmful institutional regimes and further impairment and developmental delays. (Gindis 1999; Nelson et al, 2014).

The Bulgarian approach to disability related issues, then, has been heavily influenced by the over-medicalised Soviet approach of defectology. Consequently, the assignment of disability status in Bulgaria has for decades been exclusively dominated by medical professionals and procedures, mimicking Russian practices in the area. This over-medicalisation and standardization of disability makes Bulgarian social policy particularly illustrative for exploring how certain reductions of the 'human' dominate disabled people's lives. More recent research in CEE/CIS countries (Mulheir, 2012) and in Bulgaria (Bilson and Markova, 2017, Bilson and Larkin, 2016) has included the voices of parents who have reported feeling powerless under pressure from medical professionals to hand their disabled children over to the state, often under the guise of 'a better life' for them. In some countries in CEE, some parents are reluctant to report that their child has a disability because of the shame and stigma associated with it (UNICEF, 2007).

This parental and individual disempowerment clearly relates to what Disability Studies writers have noted about the power and influence of medical professionals in reinforcing limiting medical model attitudes, leading to disabling decisions and practices for children and their families (Swain and French, 2013). In contrast, the Social Model of disability, recognises social barriers as being limiting, or 'disabling' for the child (Connors and Stalker, 2003). This is also in line with a human rights focus. The social model is therefore useful alongside child development models as it highlights how physical and societal obstacles and barriers impede the potential for

enabling environments, thus also impeding on their development. Such barriers are not confined to the poorest of countries, but represent a worldwide problem. I must add that emphasising the role of the social construction in this way does not mean ruling out the services and support provided by medical professions, but does mean that they should not dominate.

The barriers and obstacles, which can, of course, be removed, include negative attitudes in society which lead to limiting expectations for each child. Assumptions and preconceptions around disabled children being of no use to society and easily 'replaceable' lead to children being institutionalised where these negative assumptions are reinforced and compounded as children do fail to flourish as a result of disabling conditions. Another issue is the policies and practices of local and national governments, whereby the structure of health, welfare and education systems present institutional barriers. These may include a lack of physical access to buildings, transport and a range of community resources.

Further, the impact of poverty and deprivation is particularly significant in affecting families with disabled children (UNICEF, 2007:3) amongst other social, cultural, attitudinal and physical barriers that children encounter in their daily lives. To focus down further, in CEE/CIS countries Roma children, who represent the largest proportion of the orphanage population in Bulgaria, present an example of the experience of compounded and cumulative risk factors associated with institutionalisation (Roma Rights Centre, 2011). UNICEF (2007:14), recognise this as 'the particularly damaging cycle of disability, discrimination and disadvantage'.

In relation to stigma and shame around disability, it has been reported that both play a role in the placing of children with impairments, including medical diagnoses such as epilepsy and cleft palate, in institutions. This has been the case for Bulgaria, as

the UNICEF report (2007) confirms. Mladenov (2014) proposes that despite the transitional period breaking down social and cultural boundaries and bringing opportunities to challenge dated systems and ideologies, 'old traditions' die hard. He uses the example of the continuation of paternalistic personal assistance schemes, which are informed solely by medical model perspectives (Mladenov, 2011) to highlight how disabled people in Bulgaria are still denied individual agency. He also points out the dominant and widespread use of the term 'invalid' in Bulgaria, despite the change in legislation since 2005 to the term 'person with disability', which illustrates how attitudes have been slow to change.

This continuation of previous perspectives, showing the power of longstanding dominant discourses, is flagged up in Rasell and Smirnova's (2014) consideration of disability in Eastern Europe and the former Soviet Union, where they identify common visual narratives from abandoned children to dilapidated orphanages to military veterans in uniforms begging on street corners. More positive associations are much less frequent. They state that disabled people in post socialist countries 'live in a context of weak safety nets, unstable polities and ambivalent civil society development that make it difficult to overcome historical legacies of control, segregation and stigma' (Rasell and Smirnova, 2014:1).

Finally, many commentators note the difficulties faced during the transition to a different political system, difficulties which create poverty, hardship and uncertainty.

Sotiropoulou and Sotiropoulos (2007:142) comment that:

'conflict around the countries in the area of Bulgaria during and following transition, led to a complex political and economic situation which meant that the 'difficulties of revamping the welfare state after the transition from communism', this hit the most vulnerable members of the population most harshly including children.'

Bulgaria's experience of increasing institutionalisation during the period of economic transition mirrors the experience of neighbouring Romania which also increased their use of institutional care following the fall of the communist regime in 1989, largely as a result of higher rates of poverty and unemployment (Nelson et al, 2014). This was compounded, according to Nelson et al (2014), by earlier scientific isolation. They suggest that

'the tragedy for the children in eastern Europe is that the shift in approaches to child development did not happen there for the next 30-40 years. This underscores the potentially devastating effects of the scientific isolation that shrouded Romanian psychology after the second world war' (Nelson (2014:50).

2.4.4 De-institutionalisation in Bulgaria

During the early 1990s television documentaries and media reports exposed some of the harsh realities 'of children's lives in institutions in Romania following the fall of Ceausescu's regime, often incorporating disturbing images of undernourished, rocking children in overcrowded, dilapidated buildings. Accounts summarised this as a crisis. For instance, Rosenberg et al (1992) cited (in Nelson et al, 2014:6) concluded that

'there is a desperate need for an immediate international response to the current orphanage crisis in Romania. Thousands of young lives are currently being jeopardised and potentially lost. These children are not 'unsalvageable' and labelling them as such has done them a grave injustice'.

In 2007, a BBC documentary team visited a children's home in Mogilino in Bulgaria, and found examples of harsh, abusive and inhumane treatment of the 75 children living there, similar to those identified in Romania. The film presented a compelling case for immediate change for these children who were living in bleak conditions with inadequate diets, poor healthcare and without any opportunities for rehabilitation or education. This became known as the 'Mogilino Case' and sparked a public dialogue across Europe, providing part of the impetus for Bulgarian reforms around institutional care (Ivanova and Bogdanov, 2013).

The documentary was also timely in that Bulgaria was in the process of becoming integrated as an EU member and so was under pressure to demonstrate progress in social reforms including developing policies for the social inclusion of disabled children (Becirevic and Dowling, 2014). Alongside the NGO interests in Bulgaria raising awareness of human rights, EU pressures galvanised policy makers and other stakeholders to address the development of a de-institutionalisation strategy. This is shown in a study carried out in 2008 by Becirevic and Dowling, where one Bulgarian NGO stakeholder said,

‘In the pre-accession period Bulgaria was heavily criticised by the EU monitoring report on the conditions of children and people with disabilities and especially children and people living in institutions. At that time we almost had no community services and family support service and there was quite a pressure on government to start creating different alternatives’ (cited in Becirevic and Dowling, 2014: 229).

In terms of the general nature of social policy change, it is worth noting that similar conditions led up to de-institutionalisation in the UK. From the 1970s and onwards the disabled peoples movement in the UK began to grow in strength and organisations like the Union of the Physically Impaired Against Segregation (UPIAS) began to appear (Cameron, 2014). They challenged the theoretical monopoly of disability with the social model of disability which gave disabled people both an alternative narrative and voice. Further, the work of Wolfensbergers (1986) in developing ‘normalisation’ and later Social Role Validation, with the central principle being the creation, support and defence of valued social roles for people who are at risk of devaluation, became extremely influential in non-institutional design.

Jenny Morris (1997), in her account of institutional care for disabled children in the UK, highlights that the impetus for change did not happen in a political, economic and ideological vacuum. UK policy and practice began to change as a result of the new models of ‘disability’, as well as new understandings about the harmful and damaging

effects of institutional life. Policy makers were also motivated by economics, given the cost of large scale institutions. Oswin was part of the movement in the UK that closed down long stay institutions for children and her 1978 book 'Children Living in Long-stay Hospital' exposed the inadequacies of, and harm caused by, such institutions, much as Goffman (1963) had done. Her graphic diary entries about life on the wards affected many. She outlined, amongst many other factors, that physical care was poor for these children and therapeutic environments were impossible, stating that 'many children were frequently anchored all day in wheelchairs, bean bags or small armchairs, and so had no opportunities for social interactions' (1978:118). In addition, she commented that professionals were depressed by working in the inadequate oppressive environments and that (1978:81) 'the main aim of many ward staff had become how to get through the shift and complete the basic routine duties'.

To return to Bulgaria, concerns over the conditions of children grew further in response to a report by the Bulgarian Helsinki Commission (BH, 2012), an organisation aimed at protecting human rights, which revealed that at least two thirds of the 238 deaths of 'mentally disabled' (sic) children in state institutions during the years 2000-2010 (before the introduction of Bulgaria's de-institutionalisation strategy) were preventable. The most common cause of death was inadequate care, followed by pneumonia, starvation (systematic malnutrition), infections and 6 reported deaths from incidents (freezing, drowning, asphyxiation). Fifty seven of those deaths were reported during the 3 years prior to publication of the Bulgaria Helsinki Report, (2011) suggestive of the dire conditions leading up to the implementation of the de-institutionalisation strategy in 2010.

In 2014 the National Network for Children Report (2016) highlighted that positive progress had been made by Bulgaria towards de-institutionalisation targets, with a significant decrease in the amount of children being admitted to institutions, from

7, 587 in 2009, to 1,495 at beginning of October 2016. They also note that by 2015, 33 institutions had been closed down and that over a thousand children left institutional care during that year. The report also notes the successful closure of all (large scale) institutions specifically for children with impairments. Other commentators, however, remind us that figures and statistics do not necessarily portray reality, as decreases in numbers may actually be due to renaming of services (Ivanova and Bogdanov, 2013). In addition, it is also worth a reminder that 'institutionalisation' is not confined only to large scale institutions. The strategy 2016-2020 builds on the original de-institutionalisation strategy, including ensuring social and medical services for children with disabilities and improving the system in order to guarantee children's rights. However, challenges to de-institutionalisation are still present and include; political inertia, cultural attitudes and values being slow to change around disability and foster care, workforce development issues, lack of accountability and poor co-ordination of services (EuroChild 2014).

2.5 The General Impact of Institutional Care

The features of the total institution (Goffman, 1963) have been defined and considered in relation to institutional care for children earlier in this chapter. Browne (2009) suggests that care in such institutions is harmful, and characterised by an impersonal and rigidly structured round of activities and living arrangements, for example feeding, toileting, bathing and sleeping, administered in the context of a 'professional relationship', rather than one which resembles a parent/child relationship, or any other form of family connection. A report by Eurochild (2012) concurs with this, adding that institutions for children, are not designed around the needs of children, and whilst used as 'an alternative to family care', they are far removed from anything resembling typical caregiving practices and relationships in families. Dozier et al (2012:12) go so far as to comment that 'it is hard to imagine

human conditions that represent as great a contrast as institutional and family care'. In all cases they see institutional care as having a harmful impact.

Further, a report by MDRI (1999) commented on a visit to Russia where they observed children with Down's Syndrome who were 'homed' in appalling conditions. They found that:

Children believed to be uneducable and labelled as 'imbecile' can be placed indefinitely in bed in lying down rooms. In these locations, staffing may be lower than in other parts of the same facility, and it is clearly difficult for children to receive the minimal clothing, clean sheets, and food that they need. The rooms where these children live are often filled with a strong odour from urine. Although physical therapists and massage therapists provide some services, the children spend the majority of their time in bed and not engaged in any type of activity. (MDRI, 1999:20)

They note that the impact of the institutional 'care' received was developmental delay in all areas including physical development, due to the lack of movement and stimulation and not the presence of Down's Syndrome (ibid). Vann and Siska (2006) add that due to the isolation from families, inhumane and unacceptable practices such as keeping children in metal caged beds for long periods of time become commonplace. The features of Goffman's total institution are reflected in the children's daily lives of impersonal 'batch rearing', with no personal items or symbols of humanity to call their own. Children in these conditions turn to (extreme) forms of self-comfort such as rocking, chewing on their clothes and their own bodies, banging their heads on walls and cot bars and pulling out their own hair. Research from Russia highlights a stark statistic that the mortality rate for children under four years old in institutional care is ten times higher than the general population (Ministry of Health and Social Development, 2007).

The enforcement of social distance from their families and communities, in effect isolation from society, is also noted as harmful, as it leads to a lack of visibility,

overwhelming anonymity and the severe limitation of opportunities for inclusion into normal everyday life (World Health Organisation, 2010). This is exacerbated by practices in institutions whereby staff discourage family visits as they disrupt established routines, so undermining family ties (Tobis, 2000) and leading to further isolation for the children, which makes them even more vulnerable to abuse. For children with disabilities, reports consistently identify a lack of appropriate medical attention and minimal rehabilitative interaction/activity, if any at all. Most notably, for all children, one of the most damaging consequences of institutional care is the common lack of psychological investment in the child (Dozier et al, 2012; Mulheir, 2012, Every Child Rept). This will be examined in relation to child development later.

It is also well recognised, as noted earlier, that staff are also at risk of institutionalisation (Sotiropoulou & Sotiropoulos, 2007) and are therefore also vulnerable to the harmful impact of working in such an environment. Typically, institutions are staffed with poorly paid caregivers (mostly women) who work long hours on rotating shifts in bleak physical conditions (Dozier et al 2012). The poorly maintained buildings do not offer a comfortable working environment, and they are often positioned in rural areas which are difficult to reach. The caregivers need to 'detach' in order to 'survive' in caring for and protecting their own families. Staff also experience a lack of investment in their professional training and career opportunities (Sotiropoulou & Sotiropoulos, 2007).

The power of the medical professions has been identified as a key feature of Bulgaria's history of institutionalisation. In addition, Higgins and Swain (2010) see the hierarchy of the medical profession which positions doctors and consultants as experts due to their intellectual knowledge of the body as potentially harmful, as it leads to the justification of a set of objectifying practices particularly towards disabled people. Oliver (1998) notes that the medical position equates impairment with

deviancy and ‘abnormality’, which further perpetuates a deficit model of disabled people and supports questions about their perceived lack of ‘quality of life’. Such propositions lead to justified reductions in resource allocations especially for those with more severe impairments. Higgins and Swain (2010:108) argue that within such an oppressive medical framework ‘disabled children’s tendency to be objectified and dehumanised becomes heightened’, potentially leading to unsatisfactory medical treatments and procedures. The imbalance of power between professionals and patients assumes professionals know best without having to try and understand the voice of the children they are supposed to be supporting. Children with disabilities and impairments face a bleak future in institutions. Many remain there for life, only to leave when they die (Mulheir, 2012; EuroChild, 2012).

Dozier et al, (2012:6) concisely sum up the harmful impact of institutional care, stating:

‘When young children experience institutional care, social and interpersonal development is impaired, physical growth is retarded and cognitive and language development is delayed... ‘institutional care is structurally and psychologically at odds with what young children need, and that we should work to develop alternatives’.

2.6 Taking a Child Development Perspective

In looking at what might be missing in the institutional contexts regarding child development, caregiving practices and attachment in relation to the concerns identified above and the potential of the Baba project, it is now useful to return to child development theory.

2.6.1 Caregivers and attachments

Of particular relevance to this study is that the intimate, warm and responsive relationship crucial to the development of the child, is ‘particularly difficult to ameliorate within the institutional setting’ (Tarullo and Gunnar 2005:330). One of the

reasons given for this is that the organisation of institutional life involves several shifts of caregivers each day with very little face to face social contact with staff compared to children raised in families (Nelson et al, 2014). In their discussion of nursery day care in the UK, Goldschmeid and Jackson (1994) note the lack of personal intimacy in institutional life, suggesting that this has 'even more serious implications for young children as so much of the subtle communication at this age comes from touch and handling' (1994:45). This can also be assumed for children with impairments. It stands to reason that this lack of human touch is exacerbated in large scale institutions where children are contained in their cots and therefore unable to move freely in order to seek out others and initiate contact. They are wholly reliant on caregivers to 'come to them' to meet their needs. In addition, young children and children with impairments are most vulnerable to the inimical effects of institutional rearing (Dozier et al, 2012; Bilson, 2009).

The harmful impact of institutional care in terms of attachment and caregiver responses on the development of babies and young children has been pointed out in reports starting in the mid-twentieth century. In 1942, American paediatrician Harry Bakwin wrote a paper called 'The Loneliness of Infants' in which he questioned the diagnosis of 'hospitalism', noting that in the early 1900s in America the mortality rate for infants under 1 in 'foundling homes' was almost 100%. The diagnosis of 'hospitalism' was seen at the time as the result of long institutional stays which impair and damage the body causing prolonged deterioration of the body. (Bakwin, 1942; Spitz 1945). Backwin's paper highlighted that within this typical diagnosis attention was not being given to the dearth of emotional encounters in the setting and the 'lonliness' of the infant.

Sparked by these ongoing concerns about the high mortality rates for institutionalised young children, researchers began to consider more seriously the emotionally

damaging environment of the institutional regime for the infant and started to present findings suggesting that these symptoms were linked to emotional and social interactions that had previously been ignored. Research by Spitz (1945) found that in comparison to babies raised in their own homes, and others who were raised in institutional care with mother figures, the babies raised in the 'foundling homes' without mother figures had

'severe developmental retardation (sic)...exhibited high susceptibility to infection as well as markedly abnormal behaviour ranging from extreme anxiety and bizarre stereotyped movements to profound stupor (sic)' (cited in Bronfenbrenner, 1979:134).

Whilst this damage had previously been attributed to 'hospitalism', Spitz (1945) concluded that 'maternal deprivation' was the crucial factor in explaining the progressive deterioration of the infants from the foundling homes and the 'bizarre' behaviour they exhibited. Whilst subsequent critiques of his work argued for the addition of contextual factors to his analysis, the lack of the maternal figure remained core to his conclusions (Bronfenbrenner, 1979). To relate this work to more recent instances of large-scale institutional care, YouTube clips of Spitz's observations show young children in cots, rocking from side to side with expressionless faces. They could easily be mistaken for black and white grainy versions of more recent footage of institutionalised children in countries like Romania and Bulgaria, such is the similarity of the child's appearance and movement.

Bowlby's work into attachment was developing in the UK at around the same time as Spitz and colleagues in America (Bowlby, 1951). Whilst his work has been heavily criticised especially from feminist perspectives (Burman, 2008; Birns, 1999) due to his initial focus on the role of the mother, his core ideas have been revisited and refined and are still very much at the heart of understanding the development (and survival) of young children. According to Tharner (2011:11), 'attachment theory is one of the

most widely used and most extensively studied conceptual frameworks in the field of social and emotional development'. In positioning myself as a feminist, I am aware of the dangers of interpreting concepts of attachment theory in relation only to mother/child interactions. Attachment ideas have led to the reinforcement of biological assumptions about women and their role in the home, looking after babies and children. They have also been criticised for policy agendas which pathologise certain 'types' of mothers (and families) and glorify others (Burman, 2008; Birns, 1999). However, for this study, which is about the experiences of disabled children who have been placed in institutions from birth, the key concepts of Bowlby's attachment theories are useful in terms of caregiving practices.

Bowlby (1951, 1969) proposed that attachment has evolutionary roots, in that the child has an instinctual drive for survival and therefore attachment. This is played out in situations when the infant becomes afraid, stressed, and uncertain. The quality of the attachment develops as a result of the interactions with the main caregiver dependent on how they respond to the child, especially during those times of stress and fear. Children have innate strategies for maintaining proximity to the caregiver such as crying, which brings the caregiver to them. Bowlby proposed that the earliest relationships provide a blueprint for future ones, which he called an 'internal working model' (Bowlby, 1988). What can be drawn from Bowlby's work to apply to any form of care setting for children, is that it is preferable for children to have stability and continuity of care, with a key person who they can form a protective and nourishing relationship with (David, 2003).

It is difficult to mention attachment theory without introducing the key ideas developed from Ainsworth's studies which built on Bowlby's ideas. In Ainsworth's 'strange situation' experiments (1978), a lab experiment was set up to place babies into stressful situations and observe their responses during both the separation from, and

reunion with the mother. Using a rigid measuring system based on their reactions, the mothers attempts (or not) to soothe and reassure the baby, and the baby's attempts to seek proximity upon reunion, scores were allocated. Depending on these 'scores', babies attachments were classified as secure, insecure avoidant and insecure ambivalent. Later studies by attachment colleagues also identified 'disorganised' as an attachment pattern (Mains and Soloman, 1990).

In Bulgaria, and other CEE countries where child welfare systems are characterised by such institutions (Gross, 2009), there can be up to 300 children in one building. With such large numbers of children and low staff ratios, it becomes understandable to set regimented routines to complete the daily tasks, and priority would need to be on the basic needs. Such large scale facilities providing collective care make it very hard for children to get the individualised attention they need to form attachments. Numerous studies of institutionalised children have reported that high percentages of them have either disorganised attachments, typical of children who have experienced trauma and psychosocial deprivation, or 'unclassifiable' or unidentifiable attachment patterns. The latter is thought to be largely a result of the unresponsive and detached caregiving practices which dominate institutional life (Nelson et al, 2014; Rutter, 2002, 2007; Zeanah et al, 2005). Whilst some studies exploring attachment have adapted Ainsworth's 'strange situation' (1978) to use with older children (Solomon et al, 1996) others, such as Schofield and Beek (2005), have noted challenges in trying to apply attachment theory to older children in residential care who have experienced adverse childhood experiences and fragmented early relationships. In particular, Schofield and Beek (ibid) note that there are tensions around attempting to apply 'secure base' concepts, typically used in the context of infant-caregiver relationships, to the relationships being developed between older children and their foster carers, although they do argue that we must continue to try.

A recent longitudinal research study by Nelson et al (2014) known as the Bucharest Early Intervention Project, carried out a randomised controlled trial over a twelve year period comparing abandoned children reared in institutions to abandoned children placed in 'foster care intervention'. The study, which is described as 'rigorous and scientific', was primarily about how experiences (or lack of them) affect brain development. In exploring the impact of institutional care on children from Romanian orphanages their findings were overwhelmingly conclusive that raising children in such institutions leads to 'developmental hazards' in all areas. In the domains of physical, cognitive and language development, developmental deficits (sic) were significant. However, the developmental domains found to be most harmed by institutional care were emotional and social. Nelson et al reported that they,

'found a room with 12 cribs in which infants ranging in age from six to eight months, were awake, lying quietly and passively on their backs. Although we could make eye contact with them, it took considerable effort to get them to smile at us- with several we never succeeded'
(Nelson et al, 2014:51)

This is similar to my own experience as presented in the introductory chapter. What these studies show is the significance of caregivers addressing children's needs. The concept of the developmental niche, as expounded by Super and Harkness (1982), recognises that 'the greatest environmental influences on a child's development are the beliefs, values and ways of caring of their primary caregivers' (Taylor, 2012:24). Ways of caring can differ from one society to another but there are similarities in what 'good caregiving' includes (Bornstein and Putnick, 2012). According to Myers, (1992) childcare needs to include; security, shelter, clothing, feeding, bathing, supervising toileting, attending to and preventing sickness, nurture and affection, playing and socialising to the child's culture. A report by the Lancet (2016) categorises these aspects into five fundamental characteristics of 'nurturant care'; health, nutrition, responsive caregiving, security and safety, and early learning. Likewise, the WHO 'Review of Caregiving' (2004) cites a study by Bradley and Caldwell (1995) which

identifies five inseparable elements of caregiving; sustenance, stimulation, support, structure and surveillance. All of which are interdependent and all, they argue, are essential foundations from which children can thrive and flourish.

The WHO Review (2004) considers the effects of the caregiver/ child relationship on the actual survival and health of children considered most at risk. The review identifies two caregiving qualities that are vital in the provision of effective care for the child; sensitivity and responsiveness. Sensitivity refers to the caregiver's ability to treat the child as a separate individual, to see things from the child's point of view, therefore being able to understand and interpret the child's signals of their needs and wants. Meins et al (2001) use the term 'mind- mindedness' to describe the caregiver's propensity to 'read' the child in this way. Responsiveness generally refers to the caregiver's capacity to respond appropriately and promptly to such needs, but includes empathic awareness, emotional availability and stability, non-intrusiveness and a devotion to the child's well-being and happiness. These qualities of sensitivity and responsiveness enable the caregiver to respond to the child in a manner which is attuned or 'in synchrony' with the child. In writing about parent / child dyads where the synchrony is disrupted, Stern (2004) uses the analogy of 'mis steps' in the dance. He notes that like a 'dance' both the parent and the baby need to understand how each other moves and responds. Such an intimate and refined attunement to another person takes time, patience and understanding and typically happens as a result of many episodes of trial and error. Such a relationship meets the child's needs for food, warmth, safety, affection and a stimulating environment to promote growth and development, as well as also providing the caregiver with opportunities to feel effective in their role.

For children in Institution X, their caregiver (in the absence of parental or family care) is 'the institution' and the many different staff employed there. Notwithstanding the

variation in family caregiving practices across cultures globally, it is difficult to imagine how an institutional environment can emulate the caregiving practices apparent in family life. This is due to factors previously noted, such as caregiver/child ratios, lack of interaction and in some cases lack of emotional investment in the child. Also, of relevance to this research, in relation to the Babas, is that Else (2001), cited in Browne and Webb, (2005:154) suggests that, 'with knowledge based on child development' therapeutic playworkers need to have 'cultural competence' regarding their own and others' cultures. As noted by Browne and Webb (2005), this does not mean a simple understanding of the need to respect the culture of a different race or religion, but relates to an embedded and specific cultural knowledge which they argue is best positioned to support the children (Brown and Webb, 2005). Myers (1992) refers to the 'traditional wisdom' of experienced caregivers that is embedded into communities, with others referring to this informal knowledge that comes from years of 'hands on' experience as 'tacit' (cited in Bornstein and Lamb, 2011).

The significance of the lack of responsive caregivers is evident from what is outlined above and regarding the survival and health of children at risk. In addition, difficulties in forming attachments can be particularly crucial for very young children and or children with disabilities and continuity of care is critical to this (David et al, 2003). In considering older children, Schofield and Beek (2005:8) in their UK study of children living in long term foster care pointed out that 'Ainsworth's original classification model was based on established 'intact dyads' in infancy', which is very different to the caregiving experience for children who have been placed in institutional care. They suggest that for older children who have experienced adversity such as neglect, abuse, separation and loss, which has impeded their experience of building positive internal models, caregivers need to be able to adapt their parenting strategies to demonstrate to the children the features of caregiving during infancy which promote the development of a secure base. In doing so, sensitive caregivers can contribute to

the protective factors that can facilitate reversal of the developmental damage associated with the adversity or trauma during the earliest years. They propose a model which includes 5 dimensions of caregiving which will support older children already harmed by lack of attachments; promoting availability, reflective function, promoting self-esteem, promoting autonomy and promoting family membership (ibid).

Being available to the child promotes trust through knowing that the caregiver is available, 'accessible but not intrusive, dependable, and alert to signals of need, ready to provide whatever nurture and protection is needed' (Schofield and Beek, 2005:10). The liberating consequence of trust in the ability of this secure base is that children can explore, learn, thrive, and manage anxiety. Sensitive caregivers in the study were found to be able to keep the children in mind when apart. They believed that their foster children needed them to be consistently available because the children had not experienced this before. Carers described themselves as feeling central to each child's emotional well-being, acutely aware that the child was dependent on them for physical and emotional health. In this study, the carers' intense availability for their foster children was likened to the 'maternal preoccupation' described by Winnicott (1965) in relation to new parents of new born infants. From these early caregiving relationships comes a sense of belonging. Although understood differently depending on the cultural context, the feeling of belonging is captured in a report by New Zealand Ministry of Education, (2001) as,

The feeling of belonging ...contributes to inner well-being, security and identity. Children need to know that they are accepted for who they are. They should know that what they do can make a difference and that they can explore and try out new activities

Attachment is also aligned with attunement, as noted, enabling caregivers to become the child's 'safe base from which to explore the world' (Bowlby, 1951, 1969). It is the 'attunement' between the adult and child which forms the base which enables the

child to develop further positive relationships as they grow and become part of the wider community. All of these interactions and relationships are important to this study because children construct their identities and sense of who they are through others and the way they are viewed by others. As they gradually engage with increasingly wider world experiences, they also begin to see themselves as existing as a member of a family, community and culture (Music, 2011; Smidt, 2013). Being accepted for who they are, without judgement and without conditions is also the sort of acceptance that young children need from their families in order to support positive emotional development and sense of self (Roberts, 2002;56).

Feeling accepted happens as a result of daily experiences which give these positive messages to the baby or young child, leading to a positive personal identity and feelings of self-worth, as well as the development of healthy, interdependent relationships . The lack of acceptance in these terms in large scale institutions, then, is profoundly harmful. In Stryker's article on the emotional socialisation of children in Russia she noted that a particular type of attachment, which she referred to a 'toughened attachment' (Stryker, 2012: 89) has been the norm until very recently. This fitted with Soviet ideology on children and citizens as being independent and strong. When attachment theories were being developed elsewhere during the 60's and 70's, Russian policy makers did not embrace them because the key ideas were at odds with this construction of children and society. Following the breakdown of the Soviet regime, she argues that new models of thinking about children's needs emotionally, are now seeping into the childcare system, but this reminds us of the need to view models of children's development within the social context. She found that the caregivers in the institutions realised that they needed to 'train' the children in how to show affection in patterns that would make them more adoptable to Americans and other Europeans.

The significance of these approaches in relation to this PhD study is summed up by Thornton (cited in Robson, 2012:47) who suggests that 'by and large, children live up to whatever expectations their culture has of them'.

2.6.2 Attachment and brain development

In recent years, the advent of neuro-imaging and Positron Emission Tomography (PET) scanning, has led to claims that the link between early childhood experiences and the healthy development of the human brain is 'both visible and indisputable' (Cameron and Maginn, 2008:1159). Perry (1997) uses this 'hard evidence' to conclude that the early relationship is critical for children's healthy emotional development and that early life experiences have been shown to determine core neuro-biology. While not all children who suffer neglect or physical, sexual or psychological abuse exhibit outward signs of trauma, the majority of these victims 'carry their scars with them in other ways, usually in a profound emptiness, or emotionally destructive relationships, moving through life disconnected from others and robbed of their humanity' (Perry, 1997:133). These developments in neuroscience have led to further understanding about the effects of early experiences, including attachment, on the child's developing brain and the subsequent impact on all domains of development. These discussions have significantly influenced child care and early years policy and practice globally, and have also begun to appear in discussions on the impact of institutional care on the developing child (Balbernie, 2001; Gerhardt, 2014).

A working paper by a team at Harvard University likens the developing brain to the construction of a house, stressing the need to establish strong foundations in the brain architecture from which to build upon in later years. They suggest that a weak foundation can be caused by adverse conditions and experiences in the early years, leading to faulty brain circuitry. On the other hand, a 'growth promoting' environment

which provides adequate nutrients as well as appropriate levels of sensory, social and emotional stimulation and attentive care giving practices, will lead to a healthy initial architecture which will enable more optimal brain development (National Scientific Council on the Developing Child, 2007).

At birth, a baby's brain has 100 billion neurons and, during the first year of life, each of these neurons develops around 15,000 connections every second. The ongoing process of wiring and re-wiring means that new synapses between cells are constantly being formed leading to the development of, and links between, specific areas of the brain. However, through a process of 'pruning', the brain eliminates connections or synapses that are seldom or never used, leading to some areas of the brain failing to develop fully. Recent advances in brain research shows the importance of interactions with people and exploration of objects and the environment that are vital for the child's developing brain (Balbernie, 2001). If there is no time for emotional interaction, physical affection and nurturing and a child is simply fed, watered and cleaned as is often the case for children in large scale institutions (ibid), it is understandable that they may miss out on the diet of experiences that other children receive in family contexts.

In relation to this study, Nelson et al (2014) proposed that their Romanian study is really about how lack of such experiences (for children raised in harsh conditions in large scale institutions in Bulgaria) impacts on brain development, and therefore children's development. They claim that it is the absence or inadequacy of 'expected experiences' which is so harmful to children's developing brains. The 'expected experiences' Nelson et al refer to are those which are often taken for granted within a typical child rearing situation, expectations that

‘infant and young children will be exposed to sights and sounds (to stimulate hearing and vision), that an adult will comfort them when they need comforting, that adults will talk to them (to teach them language and acknowledge their presence), and that adults will provide the basic care necessary given our inability to care for ourselves in our youngest years’ (Nelson et al, 2014:2).

A study comparing children raised by their birth mothers with Romanian orphans who had been adopted approximately 3 years previous to the study, found that when cuddled by their mothers, the adopted children did not release oxytocin to the extent that the birth children did. Oxytocin is a chemical associated with warm and affiliative feelings and increases in humans when they are experiencing emotional pleasures. The findings of the study suggest that the capacity to give and receive affection, and the increase in positive hormonal chemicals associated with it, are damaged in neglectful situations (Music, 2011). Another study of Romanian orphans confirms the atrophic damage to areas of the brain and developmental delay common to children raised in extreme conditions of deprivation. Brain scans revealed significantly limited activity specifically in the area of the brain associated with language development, but even more stark findings were the almost ‘black hole’ in the orbito-frontal cortex which is the area associated most with emotional understanding and expression (Gerhardt, 2014). The circumference of the brain of children who have experienced severe neglect and deprivation is also notably smaller than children who have not been exposed to similar early experiences (Music, 2011).

Debate is ongoing concerning the ‘plasticity’ of the brain with some suggesting that the ‘window of opportunity’ can be lost for specific areas of the brain if the stimulation is lacking in the earliest months and years of a child’s life (National Scientific Council on the Developing Child, 2007). In a UK report on poverty and early intervention, Allen (2011:13) notes that ‘a lack of appropriate experiences can lead to alterations in genetic plans. Moreover, although the brain retains the capacity to adapt and change throughout life, this capacity decreases with age’. It must be noted that the

area of brain research is new and there is still much to uncover. Similarly, critics advise that brain research should be approached with caution, referring to the 'scientific' facts as 'neuromyths' (Robson, 2012; Smidt, 2013; Penn, 2005).

2.6.3 Attachment and Recovery models

Dozier et al (2012) highlight studies showing that previously institutionalised children (long term) will always lag behind children raised in families in all domains of development, but also, and importantly, that there is potential for 'recovery'. Of relevance to attachment, the concept of 'recovery' is useful to establish ways of working with children which does not involve writing them off as 'damaged' and 'irretrievable' but seeing them instead as 'salvageable' (Nelson, et al, 2014). Taylor (2012), writing about empathetic care for children with disorganised attachments in UK, suggests the use of Jacobson and Greenley's (1991) model of recovery, something which has been used in mental health. Their model emphasises certain internal and external conditions required for 'recovery' to progress. Internal factors include promoting an internal set of factors around hope, healing, the development of supportive connections and facilitating empowerment. Externally, recovery is supported by the reduction of stigma, the protection of the individual's human rights, and services that promote a positive culture of healing.

In the context of attachment, Taylor defines recovery as 'moving from the debilitating effects of early deprivation to being able to lead a satisfying, rewarding and fulfilling life' (2012:22). He also suggests that for children with disturbed attachments and trauma in their earliest years, recovery could be explained as 'becoming able to feel security developed from a trusting and caring relationship later in life' (2012:23). This process of developing attachments later in life has been termed 'earned attachment' or 'earned security'. The idea of 'intervention and recovery' in relation to introducing relationships to children in institutions is not new. Numerous studies have been

conducted which demonstrate to various degrees that children can move on from the damaging experience of institutional care, although for children who have been institutionalised in large scale institutions for long periods of time, especially for those placed from birth, the 'recovery' is less significant (Dozier et al, 2012).

Of significance to large institutional facilities in Bulgaria and other CEE/CIS countries is that they are based on a strictly medical model of care common in new member states which does not provide babies and young children with opportunities for the sensory and emotional stimulation necessary for healthy development. A range of in-depth studies have continued to present findings to argue that institutional care should be avoided for children, being particularly harmful for babies and children under 3 and children with disabilities (Browne, 2009, Herczog et al, 2004; UNICEF, 2005).

2.6.4 Resilience

Research by Werner and colleagues (1996) on a longitudinal study in America, found that some of the children in their study presented as 'vulnerable but invincible' (cited in David et al 2003). For these children, the determining factor that contributed to this 'invincibility' was that they had at least one very nurturing relationship. This quality, characterised as resilience, can be seen as an adaptation to stress, one that is only possible in the context of effective caregiving. As noted by Konner (1991:225),

'it is not stress that kills us but adaptation to stress that permits us to live. Life is uncertain. Our responsibility to babies and children is clear: it is not to eliminate stress from children's lives completely, since that is beyond our capacity; rather, it is to help shape responses to stress that will somehow permit them to live.'

This may be seen as related to what Dozier (2012:5) argues, that having a caregiver represents an "experience expectant" condition for the child, that is, an experience the human species has evolved to 'expect'. Not having a caregiver (biological or

surrogate) may exceed the capacity of young children's ability to adapt successfully (Nelson, et al, 2014). Findings regarding young children in institutional care should be considered in this context. It is now widely accepted that even where institutions have good material conditions and qualified staff, the outcomes for children are most likely to be negative (Bilson, 2009). Jack (2000: 708) proposes that for children living in family contexts, 'an enduring relationship with a special person outside of their household' can provide protective factors during times of high risk and adversity.

Global reports on all aspects of children's lives as well as reports specifically focused on children living in institutional care, highlight how childhood services and intervention programmes which are compensatory and provide opportunities for prevention, and so the development of qualities such as resilience, can become a protective factor in children's lives. This can be particularly the case for children living in social and economic disadvantage (Papatheodorou, 2012).

Whilst it is evident that preferred systems of care are influenced by social, political and cultural factors over time, these arrangements are also influenced by changing perspectives on children's development (Dozier et al 2012). In the Bulgarian context, the shift away from communist models has opened the country to newer ideas, including an influx of research on emotional development, attachment theory and brain development. This points to the need for further development of staff, (workforce development) which is one of the targets of de-institutionalisation in Bulgaria (Walker, 2011).

Carl Rogers (1959), (cited in Taylor, 2012: 24) proposed that 'in the right conditions, humans will fulfil their potential'. Contemporary research highlights key processes and conditions which underpin children's development. Bronfenbrenner's (1979) work

dedicates a whole chapter to discussing his ecological model in relation to children in institutional care, stating that

‘an institutional environment is most likely to be damaging to the development of the child under the following combination of circumstances: the environment offers few possibilities for child-caretaker interaction in a variety of activities, and the physical setting restricts opportunities for locomotion and contains few objects that the child can utilize in spontaneous activity’

(Bronfenbrenner 1979:143).

Processes are interactive, whereby the child is actively engaged in a series of ‘developmentally instigative’, continuous interactions and activities both with people and with objects in their immediate environment, and such activities are most effective when they are firmly rooted within the cultural context to which the children belong (Bronfenbrenner, 1992). This firmly suggests the limitations and implications of the lack of interaction in the large institution, and the need for any programmes of intervention to address these factors.

2.6.5 Enabling environments

In the book ‘Beginning to Play’ by Ruth Forbes (1989), she notes that in order to even begin to play, children need ‘anchors’ by which she means emotional securities. Here she is talking about Early Years settings, but the points are relevant in other settings, including the large institution. She also notes, again relevantly to this study, that for children with impairments, the exploration of the child’s own body is as significant as it is in all children’s development but that they will need an adult to support their exploration of both self and environment. This also serves to emphasise the potential significance of the Babas project, but also the limits of Institution X before the project’s initiation. Bornstein and Putnick, (2012) refer to cognitive caregiving whereby the carer provides the child with opportunities to explore the external world, mediated by the caregiver who supports the child’s exploration and meaning making by interpreting, describing, demonstrating. This is also related to what Elinor

Goldschmeid, who began her career working in institutions and became a prolific scholar on children's play, wrote when she argued that,

‘unlike adults, babies are dependent upon our imaginative understanding of what their needs are, and our willingness to provide the means by which they can pursue their own learning for themselves’ (Forbes, 1989:9).

Here she links the enabling environment and the responsive caregiver, suggesting an ideal that the space of Institution X may not permit, but that, perhaps, the interaction with the Babas can. After all, as Taylor asserts, ‘humans are social creatures and individuals act in social contexts’ (Taylor 2012:26). This reflects the constructivist perspectives on children's development offered by Piaget in terms of children's need to learn by exploration, but also the social constructivist approach of Vygotsky stressing the role of others in the organisation of the child's world of discovery (Robson,2012).

2.7 Conclusion

Since the start of this study, and up to its completion in 2018, Bulgaria has undergone some significant broader contextual changes. Looking further back to include the lifetimes of the children cared for by Babas and potentially their family circumstances leading up to their placement in institutional care, the macro changes have been enormous.

What this chapter has outlined, in addition to literature covering contextual factors such as the impact on communist theories of the family, are how child development and other disciplines are significant areas in relation to this study. The social model of disability, for instance, allows us to see that children's environments can be profoundly disabling (irrespective of impairment or not) something which is a major concern of this thesis; conversely the social model approach instructs us to look at

changing the child's environment to enable the child's development and herein lie the exciting possibilities for change extending from this research.

This chapter has also looked at environments, from Goffman's consideration of the large institution into the notion of communities and enabling environments. Of course, it may not just be the children who benefit from the Babas project, in this sense, but also the Babas themselves, building, potentially mutual resilience in response to societal change and strengthening the wider community.

Further, I have looked at how various child development theories, particularly those around attachment, contribute to the understanding of the potential changes introduced when looking at the role of the Babas. In doing so I so end directly back at my initial thesis, looking at the difference of the 'impact of institutional care on children's development', when this approach is used. This analysis serves as an effective summary and critique of large scale institutional practices and outlines their harm to the child.

Chapter Three

Methodology and Methods

3.1. Introduction

Methodology refers to the research strategy, or design, which shapes the research decisions made by the researcher (Crotty, 1998). As noted by Ramazanoglu (1992:11), 'each methodology links a particular ontology, and a particular epistemology, in providing rules that specify how to produce valid knowledge of social reality'. This chapter provides a reflexive account of the research journey and the methodological decisions I made in order to design a study which would allow me to address the research focus in a way which engages my ontological and epistemological beliefs and assumptions about research, and about childhood.

At this stage it is useful to restate the research focus and questions. The primary overarching aim of this exploratory project was to examine the perspectives of Babas, professionals, NGO representatives and volunteers to develop an understanding of the Babas' role and their potential to contribute towards the de-institutionalisation of disabled children living in a Bulgarian institution. This was broken down into four key research questions:

1. Is the impact of institutional care harmful for children? If, so, how?
2. What do the Babas do for the children?
3. What is the significance of their interactions and caregiving role?
4. Are the babas contributing towards the de-institutionalisation of the children, and what, if any, are the implications for policy and practice?

This chapter begins by presenting some biographical information which reflects my subjective positioning within the research and the qualitative research approach taken. The qualitative methodology decided upon for this study was developed from reading and analysis of literature and research texts, alongside on-going self-interrogation and reflection of how my own values, views of the world and

understandings about knowledge production have been shaped. The presentation of this biographical information therefore supports this discussion.

The narrative held with this chapter will demonstrate how the research design and methodological decisions were formed and will demonstrate how the methodological choices made are compatible with the social constructionist conceptual frameworks of Early Childhood, Developmental Childhood Studies and Disability Studies. My ongoing reflectivity will reveal aspects of the 'back stage' or 'behind the scenes' (Goffman, 1961; Hess-Biber, 2014) of the research which means being open about my own positionality and making visible the parts of the research process which are often hidden from the reader. Rather than burying these hidden elements, or pretending that they don't exist, I share some of the tensions, issues, conundrums and critical reflections along the way. This style of presentation reflects a feminist epistemology thus challenging traditional scientific research traditions whereby the researcher must remain objective, detached and value free (Hesse-Biber, 2014). In contrast, I make no attempts to convince the reader of my 'distance from the study' (Stanley and Wise; 1983, Letherby, 2003) and I view this positioning of myself throughout as a strength of the work which enhances the transparency of the process and trustworthiness of my findings. The upfront acknowledgement of my personal beliefs and values, and reflection upon how these have impacted upon the process and final product, is crucial to the qualitative research project (Robert-Holmes, 2004; MacNaughton et al, 2010), and is particularly central to a long tradition of feminist research (Letherby, 2003). The relationship and use of these perspectives will be discussed in this chapter.

3.1.1. Introducing Myself

I included the brief personal account and two personal diary entries at the start of this thesis in Chapter one as I considered this material to be of importance to 'set the

scene' for the reader. This also marked the beginning of my on-going reflexivity throughout this thesis as is typical of the qualitative tradition framing the study. The inclusion of the researcher's reflexive voice, or 'reflexivity', is a process whereby the researcher attempts to acknowledge and examine how their own social background, history, values and assumptions influences the research decisions and process (Hesse-Biber, 2014). It is an approach to 'writing up' which is widely accepted as an assumed fundamental of much feminist qualitative research (Hopkins, 2007). Such positioning of the self is viewed by many feminist writers as core to feminist research, suggesting that failure to do so leaves the reader with only a partial account (Stanley and Wise, 1983; Hesse-Biber, 2014; Letherby, 2003). This style of writing which uses the personal pronoun 'I' throughout, also serves to reinforce my attachment to the study and to take ownership and responsibility for what I write.

I introduced my personal connection to the study in terms of my volunteering experience in Bulgarian institutions, in chapter one, but there are other parts of my autobiography which have influenced the work's development, process and final written narrative. Like the children in Institution X whose experiences and development have been explored in Bulgaria's social, political, economic, cultural and historical contexts, or their 'ecological niche', my own 'presuppositions, choices, experiences and actions' (Mruck and Breuer, 2012) in relation to research and knowledge are inseparable from my life history. The decisions I made to get to the stage of completing the research and writing the thesis all relate to this, so I now provide a 'potted' autobiography to establish that, in the words of Sprague (2016:3), 'I occupy a specific location and am informed by a specific biography, which operate together to help me to see some things and lead me to overlook or even be completely wrong on others'.

In attempting to share my personal history, an immediate conundrum arises. Whilst sharing in this way is critical to achieve strong reflexivity, one of the pitfalls of such an approach is that my own voice and story becomes too prominent, potentially detracting from the voices and stories of the participants. I was also mindful that such personal reflexive accounts can be viewed as 'self-aggrandising' (Mruck and Breuer, 2003), obsessively 'overly indulgent' (Kobayashi, 2003) and narcissistic (Reinharz, 1997), which was not my intention.

Therefore, the presenting conundrum was to achieve the right balance between 'too much' and 'too little' of myself. I took time to consider the question; 'which parts of my complex life story have been most influential in framing my research choices and how much autobiographical information is it appropriate to include?' In addition, I needed to consider which parts of my life story I was prepared to share with a wider audience. Therefore, in an attempt to untangle and simplify the intricate and complex web that is 'me' (Griffiths, 1995), I have narrowed my autobiography down to four aspects which I feel present the most salient features of my life history significant to this PhD, or, the 'many selves' that I bring to the study (Reinharz, 1997). I have borrowed from Ward (1997) who, in her disability research, referred to herself as the 'wearer of multiple hats' to reflect the many selves she brought to her research process.

Of significance to this study is my 'volunteering hat' having come to the study with direct personal experience of volunteering in large scale institutions and small group homes in Bulgaria over a period of four years. Without this experience this research focus would never have occurred to me. During my volunteering visits I had not begun any formal research linked to this PhD project, but my experience of observing practice as a volunteer, as it occurred in the natural setting of Institution X and other institutions, my extensive journaling and on-going attempts to make sense of what I was witnessing at the time, was similar to that of the qualitative ethnographer

immersed in their field (Cresswell, 2007, MacNaughton et al 2010). During my volunteering visits, which included 14 weeks in total of 'hands on' work with children, over a 3 year period, I lived in local communities around the institutions and I made every effort to socialise, converse with and make friends with the local people, including staff attached to the institutions. In PhD studies which are generated by researchers themselves, research often appears to begin with the researcher's 'personal hunches' (Marshall and Rossman, 2000). This study was conceived from my experiences and 'personal hunches' as a volunteer, but those 'hunches' were also developed further when revisiting my stock of personal notes and diary entries before reaching into the literature in this area. Revisiting my written memoirs and reflections from volunteering whilst developing the initial PhD proposal is similar to a retrospective ethnography and served to support me in refining my initial ideas (see appendix 1 which includes some journal entries) and added to my overall contextual understanding.

I realised that I had been 'theorising' about life in the institution, the children's lives, and the influence of the Babas during the volunteering visits, using my existing knowledge of literature and theory to help me to understand and make sense of what I was observing. In this way, I was confirming the view of feminist writers Stanley and Wise who propose 'that 'theory' always and inevitably comes before research' (1983:159), as I was seeking to make meaning about what was going on as I was experiencing it. They refer to this on-going attempt to explain and analyse experiences as 'consciousness' which grounds all research. This 'consciousness' needed to be acknowledged and positioned as a strength from the start of my research journey and throughout the research project.

It became evident during the early stages of development, that revisiting my own words and sharing them with my supervisory team, sparked many emotions for me

that I realised I could not detach from and therefore I needed to be upfront about their potential impact. Many research scholars advise against emotional entanglement with their work (Ramazanoglu, 2002) but in this case, my strong sense of emotional attachment played a pivotal role in inspiring me to select this subject as a focus of study. Because I had worked closely with the children and witnessed what Nelson et al (2014) refer to as the 'developmental hazards' of institutionalisation and the extreme impact of the children's isolation from the public world, I felt a strong commitment to using my own academic position to attempt to share this with the wider world including academics and policy makers. It is my intention to try to make an impact with this work in terms of social justice for those children who experience institutional life as well as contributing to practice change.

In the initial stages of the design, due to this particular volunteering aspect of my autobiography, I was aware that unlike Nelson et al, (2014) who described his ability to put on his 'scientific head' in order to detach himself from the conditions in his large scale study of Romanian orphans, my own emotional positioning could not be removed from the picture. Indeed, I would go so far as to say that for anyone who has witnessed and absorbed the sights, sounds and smells of such an environment, the task of remaining 'detached' is beyond most humans' capacity. Some traditions of qualitative research propose a process of reflexive bracketing, whereby the researcher aims to recognise and then set aside their own preconceived ideas and emotions (Cresswell, 2007; Hesse-Biber, 2014). For me, this was impossible to do. I also suggest that this notion of 'bracketing off' reinforces 'positivist' notions of objectivity.

I wear my 'professional hat' as an academic, currently as a Principal Lecturer leading a Childhood Studies programme, driven by my own desire to develop skills, knowledge and experience of research in this area, and contribute positively to a

growing body of theory and research. My academic background has influenced the way I have conceptualised the study as I have drawn not only from my current academic area of Early Years and Childhood Studies, but also from my keen interest in Sociology and Social Policy, with a specific interest in the impact of policy on the everyday lived experiences of children and families. My academic interest in children's development stems from my first post education training as a Nursery Nurse at the age of sixteen, which was very much focused on traditional developmental psychology models, specifically the 'milestone' approaches of Mary Sheridan (2008) that were prominent at the time. My interest in Sociology and specifically feminist sociological perspectives began when I studied sociology 'A' level as a young mother in my twenties. At the time I was enthused by how feminist scholars exposed the lack of sociological interest in the 'private' sphere of the family, therefore ignoring the voices and experiences of women and children within this largely invisible domain. This sociological and feminist interest continued at Undergraduate and Masters' level and has been drawn upon for this PhD study. My academic interests influenced my initial conceptual understandings used to frame the study.

Further reading has introduced me to other theoretical perspectives which have stimulated shifts in my academic thinking. For example, the academic area of Disability Studies was new to me at the time I began the study. This 'academic hat' has influenced the fusion of theoretical lenses framing the study as I have drawn from many years of being positioned in and 'straddling' different academic genres as a student and as an academic tutor. As part of my sense making during my period of volunteering, I drew from much of the academic understandings and theoretical knowledge that I already had at my disposal. I pondered sociological explanations in an attempt to understand the societal factors contributing behind such large scale marginalisation of these children in Bulgaria, and I wondered about how complex wider political circumstances had combined and transpired leading to parents having

their children either removed by child protection services, or 'voluntarily relinquished' to the state with the hope of a better life for their child. Primarily concerned with the actual daily lived experience of the children, I drew from my understanding of young children's development to try to figure out which aspects of institutional care had been most damaging and what could potentially be introduced to the children to offer some semblance of 'typical' family care in most societies globally; protection, love and stimulation.

Having worked in children's settings since 1982, I also wear my 'practitioner hat' to the study. My first roles as a newly qualified Nursery Nurse in the early 1980s involved working in the two most economically disadvantaged areas of Newcastle upon Tyne. These roles, and later working as a teaching assistant in 'Special Schools', encouraged my understanding of the potentially protective role that professionals can play in children's lives. These early professional experiences strengthened my already existing core belief that this can only be effective in the context of practices that recognise and challenge social injustices and inequalities. Before university lecturing I worked in a lead role as a Workforce Development Manager for a large local authority in the North East, with a remit to develop the practice and qualifications of the Early Years and Childcare workforce in the area. This role, as well as my earlier experiences working in children's settings, keeps me rooted in the importance of developing research and theory that is meaningful and accessible to children, families and practitioners. It keeps me positioned in the applied world of 'practice' and serves as a constant reminder of the importance of conducting research which has potential to have a positive impact, to add to discussions and debates, to develop theory to inform practice, and to influence positively the experiences of children and their families for the better. The study is informed by research approaches which have a history of being committed to social change and this aligns with my own values.

The three 'hats' presented thus far sit within my 'whole life story hat' which has 'multiple strands' (Ward, 1997:33). A prominent relationship to this study, which has caregiving practices at its heart, is my own history of being cared 'for' and 'about' as a child, and caring 'for' and 'about' others as an adult. I grew up in a large extended working-class family in the North East of England with a strong sense of feeling 'connected to' and loved not only by my immediate family of parents and siblings, but also by my grandmothers, and my many aunties. Looking back on my childhood I was raised in a 'crucible' of caring arrangements consisting primarily of strong working class women who took great pride in their caregiving roles, and continue to do so. As a child, the care that I received from my female relatives provided me with a gentle and protective buffer from some of the adversity and chaos within my own immediate family, and a source of 'safety' in feeling connected to 'grown ups' who were looking out for me in their own different ways.

I became a mother myself at the age of 21 and by the age of 30 I had four children of my own. As a young mother, as is the case in families like mine, I was supported in my role by more experienced, older women in my family, who undoubtedly provided that protective buffer for my own children. My children's grandmothers played a significant role in their lives, and now as a grandmother myself to four young children I am in the position of being that older and more experienced caregiver offering another, different, layer of love, protection and connection in my grandchildren's lives. For my whole life 'caregiving', primarily by women, has been upheld as a great family, and female strength. I acknowledge the work of feminist scholars on the 'ethic(s) of care' (Gilligan, 1993; Noddings, 2002)⁶ but I am not assuming this as a pure position. Rather, I am recognising here that for this PhD study, my own history of being cared for has influenced my understandings of the 'care' that I observed with the Babas and

⁶ Goodley and Mclaughlin (2008, pp 5-7) provide a useful discussion of problematic nature of concepts of care, gender, charity and disability which are not being addressed here.

their children. It is recognised in feminist research that researchers can draw on their own biographies for sources of connection and insight (Sprague, 2016:164) and I believe that this is the case in my study. All these aspects of my own biography have led me to some insights into the Baba role which have influenced, and potentially enhanced the work.

3.2 Making Methodological Decisions

3.2.1 Epistemological reflections and consideration of paradigms

Methodology is the 'bridging' between the researcher's philosophical assumptions about knowledge, and the techniques they choose to gather and analyse data (Blaxter et al, 2001), or, the bringing together of the 'abstract' and the 'mechanical' (Morgan, 2007:123). Feminist scholar Sandra Harding (1987), distinguishes between the three elements of 'doing' the research; epistemology, methodology and method, noting that researchers often mistakenly use the terms interchangeably. She proposes that 'when we decouple the elision of epistemology and method, methodology emerges as the terrain where philosophy and action meet' (Sprague, 2016:5). However, before the philosophy and action can meet, the researcher must identify their own beliefs about the nature of knowledge and reality, and the relationship between the knower and the known. The researcher's position on this, or their 'epistemological stance at the metaphysical level', is referred to as the research paradigm (Denscombe, 2010), which provides the 'guide for a disciplined inquiry' (Guba, 1990; Krauss, 2005).

Attempting to understand and identify 'paradigms' becomes complicated because the term 'research paradigms' has many meanings (Morgan, 2007). A simple, but useful analogy is to consider the paradigm as a picture frame which can be used to showcase the same picture differently depending on the style of the frame (or paradigm) used (Macnaughton, 2010). Some research scholars claim that 'paradigm issues are crucial', suggesting that research should not begin until the researcher is

clear about which paradigm will be informing their approach (Guba and Lincoln, 1998:210). However, more contemporary approaches have explored and embraced the fluidity or potentially eclectic intersectionality of research paradigms, especially in the qualitative research traditions (Mackenzie and Knipe, 2006). The latter position reflects my paradigmatic stance, a decision I arrived at after much contemplation following some initial confusion and indecision. With commitment to reflexivity, I now present some of the epistemological and ontological issues that troubled me and explain how I arrived at my final research design.

Historically the two dominant paradigms in social science research have been positivism and interpretivism (Cohen et al, 2010; Mukherji and Albon, 2010), although many other paradigms are recognised, and discussed in research texts (Blaxter et al, 2001; Cresswell, 2007; Denzin and Lincoln, 2000; Crotty, 1998). In addition to positivism and interpretivism, writers have referred to structuralism and post structuralism (MacNaughton et al, 2010), critical paradigms and postmodern (Blaxter et al, 2001) transformatory and participatory research (Cook, 2009).

The positivist paradigm dates back to the earliest exploration of science and is based on the key ontological belief that a single reality is something that exists and can be discovered and 'known' with the use of objective and scientific methods. This paradigm, with its foundations in the empirical sciences, has an emphasis on scientific objectivity at its core (Bryman, 2008). Epistemologically, it is aligned to the belief that there is a separation between the knower and the known. For many years this dominant research approach remained unchallenged in its claims to be "value free, coherent and orderly – in fact 'hygienic'" (Stanley and Wise, 1983:6). The role of the researcher in this tradition is of one who remains detached, performing from 'behind a thick wall of glass observing nature' to ensure that the research process remains uncontaminated by their presence (Guba, 1990:20). Drawing from the natural

sciences, research in the positivist paradigm is typically quantitative, relying on numbers and measurements, and deductive in nature, usually focussed around the 'testing' of a hypothesis (Letherby, 2003).

The term 'interpretivism' is used to denote an approach which as an alternative to positivism which has dominated social science research for decades (Bryman, 2008:16). It stems from early challenges to the epistemological stance of positivism and its claims to produce universal truths. As an epistemological position, interpretivism is more typically used in social science research because it rejects the belief that the social world and the human being can be investigated through the use of objective and scientific methods. Interpretivism is therefore sometimes referred to as anti-positivist because it is not interested in the creation of true empirical studies to create grand truths that can be universally applied. In contrast, it is characterised by a concern for individual meaning and the subjective experiences of people (Cohen et al, 2007). It also assumes that knowledge is co-created within the relationship between knower and known.

In my brief autobiography I shared my own working history as a Nursery Nurse, a role which has developmental psychology, developmental 'milestones' and observation techniques at the very heart of the professional knowledge base and training. As a result of this professional heritage which has been added to in various academic roles since, as well as 'tacit' knowledge about children's development from being a mother, grandmother and Early Years practitioner, I noticed the significant developmental harm that appeared to be typical to all the children I met as a volunteer, alongside some positive developmental gains for the children who had a Baba. I was aware that I could develop a study within a positivist paradigm with a clear hypothesis stating that children's development would improve with a Babas' involvement in their lives in the institution. Using this positivist approach I could develop a range of measurement

tools that would enable me to quantify every child's developmental progress. Whilst I was interested in observing differences in the children's development, I was mindful that I was more interested in understanding the interactions between the Babas and 'their' children rather than trying to measure developmental progress. I was therefore keen to develop an exploratory approach which would allow me to seek meaning and understanding of the interactions between the Babas and children from the participants' perspectives, and to explore how the interactions could potentially add to an understanding of the role of the Babas in the children's lives during the de-institutionalisation process. Therefore, whilst the focus of this PhD explores the experiences of the children in institutional care before and during the introduction of caregiving practices from the Baba, the purpose and intention of the design was almost in direct contrast to a positivist approach.

The ontological position, or the assumptions about the 'nature of reality' most commonly associated with the interpretivist paradigm is social constructivism, which 'asserts that social phenomena and their different meanings are continually being accomplished by social actors' (Bryman, 2008:19). Researchers adopting this position assume that individuals interact with others in socially, culturally and historically located spaces, to negotiate meaning and understanding of their experiences. Knowledge is therefore co-produced. There is recognition that 'the researcher and the social world impact on each other' (Ritchie and Lewis, 2003: 63) which is why reflexivity is critical to this approach. The researcher pays attention to their own position within the research, and recognises how their own perspectives, values and previously 'negotiated meanings' come to influence the research and its findings. Social constructivism places 'great emphasis on everyday interaction between people and how they use language to construct their reality. It regards the social practices people engage in as the focus of enquiry' (Andrews, 2012: 262). In this study, the key focus of the social practices is the interactions between the Babas and the

children. Cresswell (2007) notes that the constructivist researcher seeks to understand the complexity of multiple meanings rather than seeking a narrow, surface explanation. In my study, the selection of a range of participants from different backgrounds was intended to address this by providing a triangulation of multiple perspectives giving rise to a rich in-depth understanding. Within social constructivism the researcher interprets and constructs meanings (Andrews, 2012), thus, again highlighting the need to recognise my emotional attachment to the study, my history and how this might influence the outcome of the analysis and final research story.

This ontological position reflected my own views which also reflected my epistemological position. I was therefore developing an interpretivist paradigm, which would inform a qualitative methodology and sought data collection methods which would allow for the collection of rich data. I decided that semi structured interviews and asking the Babas to keep a diary of their daily reflections for a one week period before the interview would take place would be appropriate to gather data. I also intended to analyse documents held by the British NGO. In the end, however, as discussed in Section 3.4, I focused on interview and used a limited amount of documentation only to provide further background to the study.

Tensions became evident when I started to consider the seemingly contradictory philosophical positions apparent when also trying to remain true to the research principles of Feminism, Disability Studies and Childhood Studies that were important to me. These approaches seemed true to my own position and the latter formed a significant conceptual underpinning to the study (as outlined in chapter two). I now provide an explanation of the key features of these traditions and how they reflect my approach to the research.

3.2.2 Feminist Research Influences

The application of a feminist lens to my personal history, political and social positioning, and professional situation has always made sense to me. In establishing my own epistemological and ontological assumptions, my immediate realisation was that throughout most of my adult life, feminist theories more so than any others had helped me to make sense of most aspects of my own life history both personally and professionally, and how I framed my view of how the world works. Applying a 'gender lens' to problems and areas of uncertainty has usually provided me with answers which make most sense to me. This acknowledgement to myself early in the research journey served to remind me that 'we each have a personal history with our preferred paradigm and this needs to be honoured' (Denzin and Giardina, 2009:34). I was keen to design and retain a study with feminist research principles at its heart. Feminism and feminist research comes in many iterations and as noted by Tong (2008:38),

'the idea that there is only one type of 'truly feminist' research, is as limiting and as offensive as male-biased accounts of research that have gone before. To suggest that there are simple questions, simple answers and simple definitions of what constitutes 'feminist research' is misleading as all women have different experiences of reality'

Central to the feminist movement has been the debate about the key areas of mutual understanding for feminists, and I focussed on these shared principles for this study, rather than claiming an absolute 'type' of feminist position. Skeggs (1994:77, cited in Letherby, 2003), claims that 'feminist research begins from the premise that the nature of reality in western society is unequal and hierarchical' and feminists use a gendered analysis to expose and challenge this. Whilst not intending to use a gender lens for the analysis of the findings, there are however, central themes to this study which position this research within a feminist research paradigm and position myself as a feminist researcher. Feminist research plays a crucial role in supporting social justice and social transformation (Hesse-Biber, 2014), and has an established history of

carrying out research which redresses 'the many inequities and social injustices that continue to undermine and even destroy the lives of women and their families' (Hesse-Biber, 2014:3). I suggest that the topic of institutionalisation of children is a feminist issue. It is my intention to highlight and promote the rights of children within institutional settings, and to forefront the voices of the grandmothers; the women who are taking a primary caregiving role for the children. Institutional care is provided as an alternative to a family, so, in a similar vein to feminists who have claimed the (largely invisible and 'private') site of 'the family' as a key area of analysis (Abbott and Wallace, 2005), I sought to explore 'the family' of these children, the institution, the professionals and the Babas. Like feminists who have exposed a dark side of family life (Barrett and MacIntosh, 1982) it was important for me to expose this invisible and dark type of alternative 'family' and by bringing this into a public arena, highlight the voices and experiences of women and children who have remained unheard and unseen (Hesse-Biber, 2014:3). Of course, the obvious missing voice, and one that I could not capture, is the voice of the women who have either had their children taken from them, or who have felt compelled to place their children in the institution for whatever reasons.

My lack of detachment, and hence my emotional attachment, to the study throughout the research journey also positions me as feminist in my approach. Letherby (1994:73) notes that qualitative feminist researchers should

'value reflexivity and emotion as a source of insight as well as an essential part of the research; value the personal and the private as worthy of study; develop non-exploitative relationships within research; and provide a challenge to the norm of 'objectivity' that assumes knowledge can be collected in a pure, uncontaminated way'.

My aim was that all of these facets would remain central. Stanley and Wise (1983) argue that as researchers we should make ourselves vulnerable and try and 'equalise'

our relationship with respondents, with others arguing for 'empowerment' and 'transformation' through research (Cook and Fonow, 1986:114). They propose that such an approach is central to the work of feminist researchers and refer to this as feminist praxis. Positionality forces feminist scholars to confront their socially situated selves in order to be aware of how they have facilitated and impeded different voices and understandings, to enable us to 'open up space for critical dialogue with research subjects' (McCorkel and Myers, 2003:228).

Ramazanoglu (1992:210) discusses mainstream knowledge and the notion of 'neutrality' in gendered concepts stating that 'striving for detachment is likely to reinforce the gendered nature of the production of knowledge'. It appears that taking a political line at the same time creates a new way of 'knowing and seeking truths'. However, inclusion of 'the emotional' is not without critique. Sprague (2016) also reminds us that there is a danger of the researcher failing to reflect adequately on her own experiences and emotions, and that she may also let her own emotional voice overwhelm the voice of the participants. The rationale for including my voice is supported by McCorkel and Myers (2003:203) who argue that scholars must "subject themselves to the same level of scrutiny they direct toward the subjects of their inquiry". They go on to suggest that scholars present the research results to the community concerned and that the researcher is placed on the same critical plane to achieve this. By engaging in such a process I am encouraged to continually reflect back on my study to explore how my social location and cultural assumptions have positioned and privileged me, shaping the structure and substance of the research (McCorkel and Myers, 2003).

Generally terms like 'validity' and 'reliability' are used within positivist research but are also used by qualitative researchers. I suggest terms like 'transparency' and 'trustworthiness' are appropriate for my own approach and offer alternative means by

which to demonstrate rigour and honesty within the research process. This is in line with a feminist position increasing my accountability to the reader and most importantly all the participants. Trustworthiness is concerned with credibility and dependability in research findings. Lincoln and Guba (1985) proposed that the quality of a qualitative study hinges on concepts such as validity, reliability and generalisability, but these should be replaced by the concept of 'trustworthiness', comprising the four elements of credibility, transferability, dependability, and confirmability. In this sense, rigour is considered to be achievable through the use of strategies such as prolonged engagement with participants, continuous observation, using different triangulation techniques, debriefing with peers, and checking back with respondents (Lincoln and Guba, 1985). I have attended to each of these during this research process and they are discussed throughout, but primarily it is my level of reflexivity in telling the story of this research and my own role within it, which enhances the trustworthiness of this project.

3.2.3 Disability Studies Research Influences

Although the research is primarily influenced by my allegiance to feminist traditions, as the children in the study are disabled children I was mindful of key themes of research approaches in the academic area of Disability Studies. Some aspects are similar to feminism in that it is a social discourse rooted in a strong political movement, which aims to redress social injustices and it challenges oppressive research regimes and notions of enforced objectivity common to traditional empirical approaches. Like feminist research, it aims to remove the hierarchies of the classic research design and its primary objective is to improve the quality of disabled people's lives (Barnes and Mercer, 1997; Cameron, 2014).

This research has the added dimension that most of the children who are indirectly involved have impairments, and according to the social model of disability which was

introduced in chapter two as a useful conceptual position, have therefore been 'disabled' by features of their environment and societal barriers to inclusion, not by their impairment. This has led me to consider the design of the study through the lens of Disability Studies which reminds researchers to reflect and question how they work to create space for the marginalised voices of disabled people (Ashby, 2011; Jones, 2007). Further, as Cameron and Moore (2013:38) assert that 'the role of research in disabled people's lives has to be scrutinised to ensure disabled people play a meaningful role in the inception, conduct, analysis and dissemination of enquires that will impact on their lives' (ibid). Taking this further, Oliver (1996:114) states,

'As people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than as part of the solution. Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life.'

Barnes and Mercer (1997) in their key text entitled 'Doing Disability Research' emphasised the importance of undertaking emancipatory research with disabled people located in the social model of disability. The aim of disability research is therefore being able to witness, record and present the voices of disabled people in terms of an emancipatory posture. It also intends to challenge the social exclusion and disadvantage often faced by disabled people (Cameron, 2014). Cameron writes that the history of traditional disability research is one based on an unequal power base where disabled people are subjects to having their problems measured. Barnes et al (1999:213) state that disability research is designed to

'overcome the perceived shortcomings of mainstream social research which has been immersed in an individual approach and guided by policy and professional agendas to generate more information on the service needs of disabled people in order to help them better cope with their 'personal tragedy.'

3.2.4 Childhood Studies Research Influences

Central to my study was the desire to move beyond the ‘measurement’ approach which treats the child as a passive object of study, or, as stated by Alldred (1998) a ‘specimen under the scrutiny of the scientist’ (Greene and Hogan, 2006:115). Of relevance is that the dominant models of developmental psychology which have informed research and practice with children especially in childcare and educational settings, have their historical roots in positivism (Aubrey et al, 2000:31). From the late nineteenth century and for much of the twentieth century research with children was dominated by approaches which align themselves with distinctive features of empirical investigation associated with a positivist approach, or ‘scientific inquiry’ (Clarke et al, 2014:35). Such approaches relied heavily on statistical analyses to identify causal relationships which produced grand theories about the developing child, but were challenged for the lack of attention paid to the social context of children’s development. Childhood researchers began to feel uneasy about the positivist claims of ‘objective truth’ (Clarke et al, 2014) which was part of wider critique of positivism within the Social Sciences (Cohen et al, 2007) at the time.

Classic attachment studies such as Mary Ainsworth’s ‘strange situation’ (1978) are built around measuring and classifying attachment behaviours in the carer/child dyad, using ‘measurement’ tools and emphasising the objective ‘behind the glass mirror’ approach in ascribing attachment ‘types’ to young children. Likewise, large scale studies of institutionalised children, such as the work of the Bucharest Early Intervention study (as highlighted in chapter two) have also taken positivist approaches to create and maintain ‘scientific rigour’ (Nelson et al, 2014). Whilst I knew I would be drawing from the results of these studies to inform the literature framework and in my analysis of findings, I sought to actively avoid the approach whereby children are ‘passive objects disconnected from their context’ (Mukherji and Albon, 2010). Whilst I am drawing from attachment theory I have aimed to do so in a

selective manner, using ideas that I believe to be applicable to this study, and to offer exploratory frameworks for analysis of the data. However, still acknowledging the limitations of attachment theories.

This research is more influenced by the approach that Kay and Tisdall (2012: 184) highlight, stating that 'childhood and disability studies both positioned themselves as counter paradigms, as severely critical of what has gone before'. Another point they make is that both children and disabled people, and indeed disabled children, have been subject to considerable research inquiry as passive recipients of the 'professional gaze'. On the one hand I am also falling into the trap of the 'professional gaze' by opening up the world of the Institution X and looking in from my privileged position. However, research in this area is scarce and change can only happen if their stories are told (Rassel and Smirnova, 2014). I am confident that I am carrying out this research in a respectful manner, being constantly mindful of any potential harm that could be caused, and staying true to my intention of foregrounding the Babas' voices as the ones who know the children best. In this way remaining true to my commitment to producing research that will work towards minimising their disabling anonymity and isolation. My reflexive stance supports this endeavour.

3.2.5 Reaching a decision.

In research texts these approaches (Childhood and Disability) are most typically listed as sitting outside of an interpretivist paradigm as is feminism. They are referred to as 'critical paradigms' as they challenge the status quo. Herein lies a conundrum which troubled me; on the one hand I was aligning with Feminism, Disability and Childhood Studies which are generally regarded as 'critical paradigms', but my own ontological and epistemological assumptions were also reflective of a broadly interpretivist paradigm which 'looks for culturally derived and historically situated interpretations of the social life-world' (Crotty, 1998:67). A concern for me in expressing an interpretivist

paradigm is that such an approach has been challenged for not being critical enough (Crotty, 1998) and for not placing enough emphasis on social action for change (Cresswell, 2007). In a sense it is not concerned with value and subjects as political. Although I sought to understand the subjective meanings of individual 'actors', and I acknowledged that my own interpretations of the research are bound within my own history, I was keen to understand aspects of power, inequality and social injustice potentially exposing oppressive structures, practices and attitudes which lead to the institutionalisation of young children in the first place. In doing so, I wanted to promote a voice for the children through the Babas and other participants with the ultimate intention of improving their lives. Cohen et al (2000) refers to this type of approach as a 'critical paradigm' which has emerged from an increasing recognition that positivist and interpretivist paradigms are lacking in political and ideological conscience, with accusations of 'political inertia' (Berry, 1986).

A difficult tension is that by presenting a study as a 'snap shot' or 'one story' of interpreted meanings and realities for one small group of people in a particular place, time and historical context, in this case, the children in Area A of Institution X, it is then difficult to present this as a 'truth' of injustice which must be opposed. I had concerns about what the interpretivist position, with its fluidity and negotiated meanings, appeared to be assuming about truth. In the interpretivist paradigm it is difficult to claim one truth, which means that it might be difficult to then develop social action for change as the assumption is it could be argued that there no fixed 'truth' to oppose and challenge.

I was troubled that I hadn't identified *one* paradigmatic position as a starting point and that the paradigms reflecting my own assumptions about knowledge appeared to be contradictory. Many of the research texts that I read early in the development stage presented neat lists of 'paradigms' with their key features and characteristics divided

and contained into tables and boxes (Cresswell, 2007; Denzin and Lincoln, 2000; Crotty 1998) whilst my own approach appeared to be less fixed than this and I struggled to align myself and my study to one concrete paradigm. Even the process of having to identify a paradigm jolted with my view of my own knowledge construction.

As I became clearer and more confident about what I wanted my own study design to look like, I found the definition of a paradigm offered by Bogdan and Biklan (1982:30) useful. They refer to a paradigm as 'a loose collection of logically held together assumptions, concepts, and propositions that orientates thinking and research' (Krauss, 2005:105). I liked the emphasis on 'loose collection', as I had decided that whilst my overall paradigm was interpretivist, I was also clear that certain key features and themes drawing from Feminist, Disability Studies and Childhood Studies research would be central, especially in my approach to the study. In writing about qualitative traditions, Barbour (2014:28-45) confirms that the adoption of 'hybrid approaches' is now more typical and acceptable amongst qualitative researchers, advising them not to worry about 'nailing your colours to the mast'. Similarly, Bryman (2008) notes an overlap of paradigmatic stances is increasingly common to qualitative research as a result of the nature of the issues, topics and settings researched. Other writers have referred to this as the 'messiness' of qualitative methodology (Cook, 2009), which can allow more creativity and ultimately lead to greater impact in research. In summary, given the complexity and intersectionality of culture, gender and disability, a neatly compartmentalised or 'boxed' approach is insufficient in explaining the complexity or mess in the area. I was reassured when I read Dillard's view that "dominant paradigms should be subverted. Scholars should be encouraged to embrace a militant particularism, individual paradigms that embody, and reframe enquiry 'as a healing process, as a process of being in the service of social justice and social change' (Dillard, 2006:65).

I was aware that I was falling into the trap of what Janesick (1998:48) refers to as 'methodaltry' or, 'the slavish attachment and devotion to method' approach used by some academics. This reflection and questioning established my conviction that research does not necessarily conform to a specific template or design, rather it is a 'practical matter that must be adapted to the particular circumstances in which it is carried out' (Clarke et al, 2014:5). It is bespoke in nature. I therefore decided on an overarching qualitative methodology straddling paradigmatic boundaries as demonstrated in Fig 2 below.

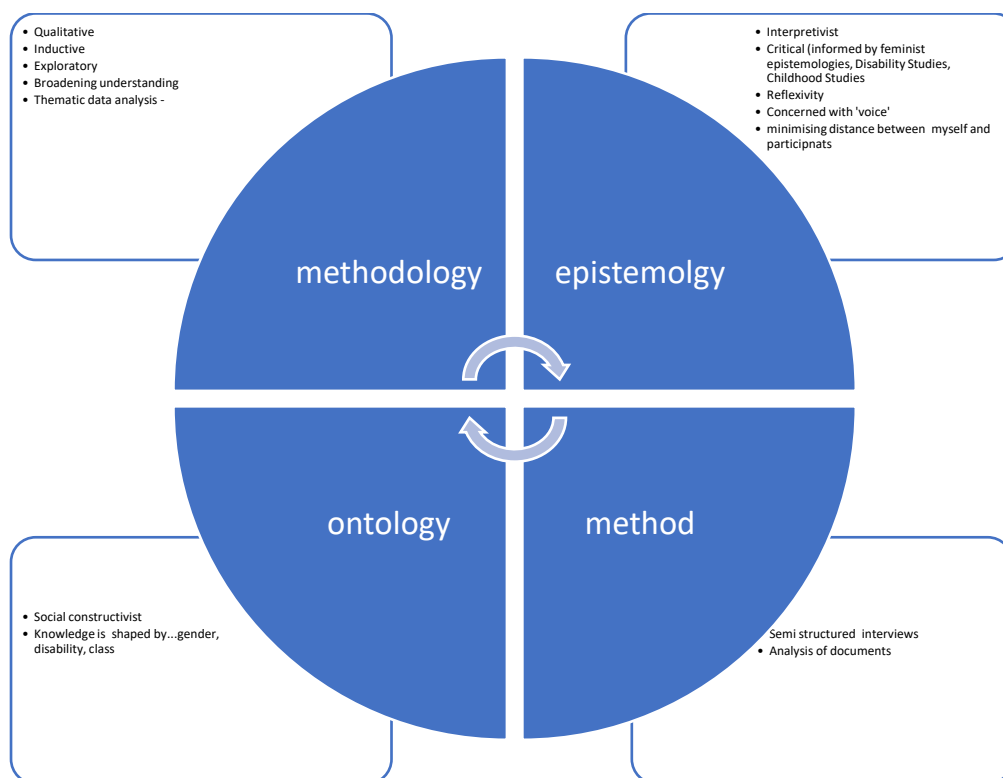


Fig. 2 methodological decisions

An eclectic qualitative methodology therefore allowed me to explore the inclusion of the Babas in the children's lives through the Babas' own eyes, and through the understandings of the professionals and volunteers who worked alongside them. Qualitative research allows for an 'in depth' study of the 'how's', 'what's' and 'whys' of this work leading to an 'interpretation' of the meaning of their caregiving practices with

the children. Qualitative research is a predominately inductive paradigm, whereby the meanings and patterns emerge as the research progresses, rather than beginning with a set hypothesis which data is tested against (Cresswell, 2007). In this way, theory is generated from the data collected as opposed to a more positivist deductive approach whereby theory is presented and measured against.

3.2.6 Reflecting on my positionality

Qualitative researchers believe that the best way to gain understanding of what is happening in any situation is to become immersed in it, to become part of the culture, system or organisation being studied, and to experience what that feels like themselves (Krauss, 2005, Aubrey et al, 2000). In developing the research design it was evident to me that my position as a volunteer, and a voluntary 'employee' of the British NGO working in the institution needed to be explicitly considered as this would undoubtedly influence the choices before me in all aspects of the PhD journey. I had already become a part of the community of the institution, albeit not a full member, before embarking on the research project, which meant that I had considerable experience and information which would assist me in developing appropriate research questions using suitable methods (Aubrey et al, 2005).

I felt I had already established a trusting relationship with the Babas and the professionals working alongside them (Corbin and Buckle, 2009). The difficulties faced by 'outsider' researchers has been examined by Szenasi (2010) who notes the tensions involved in trying to develop trust when being perceived as undertaking research from our 'privileged' position. I felt due to my previous volunteering role I had made some steps towards minimising this perception of myself as an 'outsider', although as both a volunteer and then as a researcher I was acutely aware of my 'privileged' position. This will be discussed further when I explore some of the challenges I faced during the data gathering phase. Corbin and Buckle, (2009:58)

note that: '*Insider research* refers to when researchers conduct research with populations of which they are also members so that the researcher shares an identity, language, and experiential base with the study participants'.

Whilst it was evident using this definition that I could not begin to consider myself a full insider, in some ways I was a 'partial insider', or an 'inbetweeners'. Naples (1996) suggests that insider/outsider positions are not static, but rather, positions of the researcher are flexible and ever shifting, therefore the binary of 'insider' or 'outsider' is a false one. Regardless of where I sat on the insider/outsider continuum, without this 'insider knowledge' my project would have been more difficult, perhaps impossible. I also argue that this insider position increased the likelihood of collecting 'quality data', and the 'insider insight' I had developed guided my methodological design as outlined here:

- I had been to the institution many times and had met and developed either personal and/or professional relationships with all of the participants before I embarked upon the research project. I had an insight to their levels of spoken English, the demands on their time and the potential to be involved willingly as participants to be interviewed.
- I had met, cared for and *cared about* (Noddings, 2008) all the children before my research project began, which meant that I was aware of their very fragile physical health states as well as the extreme levels of developmental harm. I knew that realistically they would not be able to actively participate in the data collection given the limitations within this small scale study.
- I had worked in a key role alongside the director of the British NGO as well as having developed a good and trusting relationship with the lead psychologist

at the institution. I knew that they would act as gatekeepers in helping me to gain access to the participants.

- I led a different project at the institution some years previously and I knew that all the volunteers had been encouraged to keep journals about their experiences as a means of coping with the emotionally challenging nature of the work. I knew that the volunteers would be willing to share their thoughts with me.

3.3 Ethical Considerations

This study from the start has provided me with many challenges to my own assumptions, values and beliefs, and has been responsible for many shifts in my own thinking and understanding of the subject area. The ethical dilemmas I have faced stand out as providing me with the most significant challenges of all, and have continuously required me to dig deep in questioning myself, my role as a researcher, my understanding of the research process and my choice of research design. I have been troubled with trying to negotiate an ethical position which allows me to accept that I, as an academic, will benefit from completing this PhD. The notion of researchers benefitting from research more than the groups of people they research (Macnaughton, 2010), is particularly troublesome for me.

I include this discussion of some ethical challenges here before, and separate to, the 'procedural' aspects of ethics, because these considerations contributed to the research design. This follows Aubrey et al's position that 'our moral philosophy or set of moral principles define our ethical stance, which in turn will decide how we conduct our research' (2000:156). These 'axiological' considerations reflect and reinforce my epistemological underpinnings in the positioning, sharing and owning of power in conducting research.

I was always mindful that I would not view the 'ethics' section simply as the 'disembodied and detached' 'hurdle' of getting through the University's approval panel (Hopkins, 2007, Macnaughton, 2010), but as an on-going venture into an abyss of, at times, soul searching questions and dilemmas that would ultimately support the development and progression of a sound PhD study, a study that I would feel comfortable with. In her discussion of the politics and ethics of 'care', Noddings (2008:23) highlights a criticism that academics become too distant from the actual lived experiences of 'the researched'. She notes that:

'the tendency towards abstraction is illustrated in much political and social theory. The temptation to create grand schemes and universal narratives is hard to resist once we move into the public realm...those who create the theories begin to serve them by defending, revising and extending them. Others get caught up in debates over them, and those needing care may be all but forgotten.'

I was committed to remaining attached to the lived experiences of the children and adults in this study, which fits with my own positionality and reflexivity, and being upfront about my own ethical considerations explains some of the design choices. Although there are a plethora of ethical guidelines available for researchers conducting research with children either directly or indirectly (Alderson and Morrow, 2011; Palaioologue, 2012; Tisdall et al, 2009; Flewitt, 2005), there are always areas of ambiguity where the researcher must rely on their own interpretation of what is 'best and ethical' practice. Using my own ethical and moral compass and intuition in this way was pivotal to some of the decisions I made along the way.

One of the decisions made very early in the study was that I would continue to 'give something back' as a volunteer as far as was feasible to do so (I discuss my attempt to do this in the data collection phase section). I felt that this served to resolve some of my anxieties about my professional gains from 'doing a PhD' and it seemed a more ethically acceptable position in that I was giving something of myself in return for those

gains. Furthermore, different societies and cultures tend to have different and competing perceptions and understandings of what ethical research is (Hopkins, 2007). Silverman (2002:331) notes the dangers of 'ethical universalism'. I was careful to continue to have conversations with Bulgarian 'friends' who I used as soundboards for this work. Again, this adds to the trustworthiness of the research.

One ethical issue that I pondered most frequently, was how to justify a study which did not include the voices of the children themselves. The increasingly significant ideological shift in the field of ECD and Childhood Studies towards perceptions of the child as a social being with agency, with the capacity and 'right' to participate and to have their voices heard and respected (Alldred, 1998; Palaiologue, 2012; Brooker, 2008) is now recognised internationally in the United Nations Convention on the Rights of the Child. Specifically, Article 12 states that:

'State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child' (UNCRC, 1989).

I was also mindful of the 'no research about us, without us' position espoused in Disability Studies (Harrison et al, 2002; Cameron, 2014) that no research should be conducted 'on' disabled people but it should be with or led by them. Writers in this field remind researchers to reflect and question how we work to create space for the marginalised voices of disabled people (Jones, 2007). In relation to disabled children, Visweswaren reminds us that 'young children with SEN are experts on their own lives' and it is the duty of the researcher to 'give voice to the voiceless' (Visweswaren, 1994, cited in Thompson, 2008:3). Similarly, Ellis and Beauchamp (2014), note that children with complex impairments still have the same right to participation in the research process even if their inclusion makes it a more challenging task for the researcher. They state that 'even children with severe learning disabilities or very limited expressive language can communicate preference if they are asked in the right way

by people who understand their needs and have the relevant skills to listen' (Dept. of Health 1991:4 cited in Ellis and Beauchamp, 2012).

Following this line of ethical thought it was therefore my responsibility to design a study that could somehow include the children from 'Area A'. I wanted to find out about the extent to which the Babas could influence the children's experiences of life in the institution, and for this reason I would have preferred to develop a study that included the children themselves as participants. I also contemplated how I would design a study to best include and reflect these voices and experiences. A fully ethnographic study would have been appropriate with observations of the intimate interactions within the everyday routines children and their Babas. This would also have provided an ideal multi modal method of capturing data (Flewitt, 2006) which would have allowed for further triangulation.

A report by Bilson and Cox (2005) examining the state of institutions in Sri Lanka did include the voices of the children as key informants and advisors. Researchers stayed for five days in each of the eighty-four institutions studied, during which time they were able to observe practice as well as conducting interviews and focus groups with the children, professionals and care givers. This design was attractive in capturing such a large scale picture, however, I was aware of the small scale nature of my own PhD study and feasibility. Many of the children in my study are much younger, they have impairments and complex medical needs and have not yet acquired spoken language. They are also children who show obvious signs of harm due to long term malnourishment. The amount of time to build up trusting relationships and develop appropriate research tools with the complex needs of these children in mind would take substantially longer and would have jeopardised the project being able to go ahead. Such intense scrutiny could also have potentially impacted on the developing relationships between the Babas and the children.

The research therefore became ‘one step removed’ from the children as I decided that the children would not be participants in the research. The research is *about* children’s experiences but these experiences are reported through the voices of the adults participating in the research. Parents and carers, in this case the Babas, professionals and volunteers, can provide a unique insight into the daily lives and experiences of disabled children and the challenges they may face (Ellis and Beachamp, 2012). It seemed ethically appropriate to use the voice of the Babas as the key voice for the children as they appear to be the nearest to a parent they have. It is however still important to be aware of any power imbalance throughout the research.

The ethical considerations for this research have generated a complexity of language and cultural barriers that need addressing, as well as the political sensitivities involved when a researcher attempts to enter one world from a completely different perspective. As noted by Moore (2010:113) ‘the only people who can successfully engage fully with local people, and get them to reveal their true thoughts and feelings are people who are truly from and still part of the community’.

I was uncomfortable with my position as a non-disabled western researcher, and troubled by my position as a British woman carrying out a study in Bulgaria. I was aware that I would be viewed as ‘that researcher from the university abroad’ (Watson, 2011:210) and could be considered in part as advocating a colonialist research agenda. I was respectful of this and remained focused on the ethical values demonstrated in a quote by Denzin (1989:83) stating: ‘our primary obligation is always to the people we study, not to our project or to a larger discipline. The lives and stories that we hear and study are given to us under a promise, that promise being that we protect those who have shared them with us’.

I have outlined some thoughts and tensions I experienced in developing a study which would address ethical concerns about research indirectly involving children. I have explained my desire to be mindful that ethical considerations are on-going throughout the project and not simply concerned about the stage of contact with the participants (Alderson and Morrow, 2004). I now outline some of the more pragmatic aspects to ethics, including the application of the requirements of Northumbria University's Research Guidelines (Northumbria University, 2011).

As noted in Northumbria University's guidelines: 'Informed consent is one of the core ethical principles of conducting research with human participants and with named data. It is embodied in ethics guidelines, including the ESRC's Research Ethics Framework (September 2012) in which two of its six core principles are:

1. Research staff and subjects must normally be informed about the purpose, methods and intended possible uses of the research, what their participation entails and what risks, if any, are involved. Some variation is permitted in very specific research contexts.
2. Research participants must take part voluntarily, free from any coercion. Informed consent is regarded as so important because it respects the autonomy of the participants, and because it protects their welfare (the individual being best placed to judge whether something is unduly risky or harmful to them). There are three main elements to ensuring consent:

- Adequate appropriate information to make an informed decision.
- Voluntariness (with no coercion or undue influence).
- Competence and/or autonomy'.

In order to comply with these principles 'informed consent' I developed paperwork, which was shared with participants at critical points, during the research. This will be referred to when I discuss the process of 'doing' the research and is contained in the appendices.

3.4 'Doing' the Research

'a methodology works out the implications of a specific epistemology for how to implement a method' (Sprague, 2016:5)

The chosen methods were suited to the research questions although, as previously noted, I would have preferred a fuller design using a range of methods which would have facilitated more effective triangulation of data, a step towards ensuring increased reliability (Cohen et al, 2010:112-114, Silverman, 2015). In my initial proposal, I had planned to ask the Babas to keep a written diary for a period of one week to gather detailed notes about their role with the children, which I would then scrutinise with the assistance of my translator prior to the interviews. My intention was to use these diaries as a basis for the interviews as well as using the pre-set interview questions.

The qualitative research design does not allow for a detailed plan before the research begins, 'the research must therefore be 'played by ear'; it must unfold, cascade, roll, emerge (Lincoln and Guba 1985:203 in Pickard). This was the case for me, as I was advised by the lead psychologist that the Babas would find this too intrusive and time consuming in their already busy lives. As a volunteer in the institution I had observed on many occasions the interactions between the Babas and the children. Ideally, it would have been useful to carry out in part an ethnographic study which would involve observations of the children and their Babas formally in order to be able to capture and scrutinise in depth the more subtle aspects of their relationships. A skill of the doctoral student/researcher is to accept the boundaries and limitations of a project and to pursue an inquiry within realistic parameters. I had to accept that time and

'political sensitivities' would not allow this and I decided that semi structured interviews would be the most appropriate method, alongside some analysis of existing documentation held by the British NGO.

3.4.1 Semi-structured interviews

To gain an in depth understanding of the Baba project, I needed to gain valuable, elaborate responses, therefore semi structured interviews were used to capture the thoughts and opinions of the different participants. The decision to use semi-structured interviews was governed by my desire to see the world as closely as possible from the perspective of the participants, to gain an understanding of how and why they came to their particular view of the world and make sense of their experiences (King, 2004). Qualitative interviewing 'has been particularly attractive to researchers who want to explore voices and experiences which they believe have been ignored, misrepresented or suppressed in the past' (Byrne, 2004:182 cited in Silverman, 2015:114), and this aligned with my desire to highlight voices that were not typically out in the public arena. I also believed that this style of interview would be adaptable (Bell, 2005) which would be useful for a broad subject area.

My lack of understanding of the Bulgarian language was a key factor in selecting a semi structured interview as I was not sure where the questions with the Bulgarian participants might take me, especially as I was using an interpreter. Using the semi structured interview, I felt that I would be able to 'follow up ideas, probe responses and investigate motives and feelings,' (ibid;157). This proved to be less straightforward than I had assumed due to reasons discussed later. The interviews were not based on a strict interview schedule which had to be followed, but on a flexible interview guide (see appendix 2.). The questions were developed based on the overarching focus of the project, my personal understanding of life for the children in the Institution X and my diary entries, and informed by my understanding of the

academic literature in the area. I aimed to develop straightforward questions that would elicit thoughts and responses without putting unnecessary pressure on the participants. I believed, from previous informal observations of their behaviours in the institution, that the Babas may feel intimidated by questions that appeared to 'test' their knowledge so I wanted to keep questions as open and non-threatening as possible but still allowing the gathering of reliable data.

I was aware that the language barrier would serve as an obstacle to a more desirable free flowing conversational style of interviewing, but I did intend to take a feminist approach which involves the participants as 'conversational partners' and 'equal participants' rather than as 'research objects' (Fontana and Frey, 2000). I had developed relationships with the participants due to my voluntary work experience and I wanted to achieve as far as is possible, a conversation between equals, rather than the conventional approach whereby the interviewer holds the power (Fontana, 2003). This style of interview was intended to provide the participants with a voice and the opportunity to describe their understandings of the research focus, in this case the role of the Babas, in their own terms.

3.4.2 Developing the interview questions

The development of interview questions, which takes careful consideration (Mukherji and Albon, 2010) presented me with some struggles as I was aware that the semantic understanding might be different from a Bulgarian perspective, an issue noted by Twinn (1997) in examination of validity and reliability of research when using translators. She emphasises the importance of the researcher being mindful of the translation of cultural meanings of words from the early stages in the research process, including the development of the research tools, although she also acknowledges the additional role of the translator here. In developing the questions I also wanted to avoid 'impairment focused' questions presenting a 'deficit' model of

the child. Disability Studies writers note that common to a deficit (medical) model are words like '*cannot*' do, or '*has*' in naming a 'condition' (Swain et al, 2005). I was therefore conscious of avoiding this approach when asking questions of the Babas. I therefore worded one of the questions, 'tell me about child 'A' when you first met him, what could he do?' I wanted to avoid questions that inferred a construction of the 'passive' medicalised child. In essence I wanted to develop a limited number of straight forward questions that encouraged Babas to talk freely about their role. Using questions like 'tell me about your child' invited open ended answers.

I reflected on my own experiences of working alongside the Babas and pondered how they might 'receive' each question. I piloted the questions on a friend who had also worked as a volunteer so she had an understanding of Institution X. The pilot interview helped me to identify some additional supplementary questions.

3.4.3 Sampling

Before gaining a sample access needs to be negotiated so I sought permission from the two main gatekeepers. I approached the Director of the British NGO overseeing the Baba project to seek permission to carry out the research and permission from the Director of the Bulgarian NGO who leads on the Baba project in Bulgaria. I had access to all of the volunteers through our existing social network of volunteers. The NGO Directors were both given a letter (see appendix 3) which outlined the project and requested permission for the research to take place. Both Directors as gatekeepers, gave their permission by signing the letter to approve the research.

The sampling approach taken for this study was purposive which involves a conscious judgement on the part of the researcher about who is included as a participant, and who is not. The judgement is based on the researcher's need to choose participants who will be able to provide data to fulfil the specific purpose of their research (Cohen

at al, 2010), namely, participants who are most likely to have experience or expertise to provide quality information and valuable insight in to the research topic (Denscombe, 2010). The sample is not required to represent the wider population and is 'deliberately and unashamedly selective and biased' (Denscombe, 2010:104). In this case, to conduct an in-depth exploration of the Baba project, the people who I believed to be the most able to provide the most valuable insights fell into three categories. Firstly, I was keen to forefront the Babas' voices in the study. This was influenced by a feminist research principle as I wanted to 'reveal the subjugated voices of women' (Hesse-Biber, 2014:78). With my insider knowledge of the project, I knew that whilst the Babas reported back to the psychologists, the final voice which contributed to the children's records was that of the psychologist. However, I also wanted to include other voices which would add to the data and provide a fuller picture which in turn could add to the triangulation, integrity and trustworthiness of the data, (Ritchie and Lewis, 2013). I therefore also sought the views of some of the professionals involved in overseeing and implementing the Baba programme (sample group 2), as well as some of the British volunteers who had worked alongside me in 'Institution X' and other institutions for long periods of time (sample group 3). Consequently, there are 3 sets of participants within the study design: Group 1- Babas, Group 2- professionals working in institution X and the NGO representatives, and Group 3 -the experienced volunteers from the UK.

Sample Group 1- the Babas

Group 1 were approached through the lead psychologist Todor who was also a participant, acting as a gatekeeper after I provided him with a list of questions (see appendix 2) and information sheet (see appendix 4) to show the Babas⁷. On the day of the interview with the support of a translator the information sheet was discussed

⁷ These were translated into Bulgarian for the Babas and other Bulgarian speaking participants.

and they signed a consent form (see appendix 5). My initial intention was to interview 10 Babas, however due to the timing of my visit, there were some Babas absent which meant that I could only interview six. All the participants in this sample group are retired Bulgarian women who are grandmothers themselves and who are employed by the NGO managing the Baba programme.

Most of the grandmothers are over retirement age although out of a sense of respectful politeness I did not ask their actual ages. The NGO director and the lead psychologist selected the six Babas who were the most experienced as they felt that their insights would be most useful for me to address the research objectives. All of the Babas are Bulgarian and do not speak English. The initial contact about participating in the research was made by the Director of the British NGO who oversees the project. She mentioned my study to the Babas on one of her visits to the institution prior to the study taking place, and requested their permission to be interviewed by me. The Bulgarian, English speaking, psychologist (Todor) also reminded the Babas of my forthcoming visit nearer the time and again confirmed their willingness to take part. I had forwarded details of the study to him and he passed this on to the Babas. Each Baba cares for 2 children (child 1 and 2). At times during the interviews when providing examples, they referred to these children as well as others they have cared for in the past. I have therefore also included the names of the children that each Baba referred to in the table below (table1).

Table 1- sample group 1

Baba Name	Child 1	Child 2
Baba 1 Petya	Rositsa F	Hristo M
Baba 2 Violeta	Penka F	Daniela F
Baba 3 Ekaterina	Gheorgi M	Michele F
Baba 4 Rositza	Ivan M	Desislav M
Baba 5 Elisaveta	Rumen M	Nikolai M
Baba 6 Margarita	Dida F	Denis M

Sample Group 2 – the professionals in Institution X and NGO representatives

Group 2 were a purposeful sample born of my own contacts in the UK and in Bulgaria, the psychology gatekeeper and the leader of a UK based charity. They were emailed information sheets (see appendix 4 and consent forms (see appendix 5) and I met with them both in the UK and Bulgaria. They were 4 professionals working alongside the Babas in Institution X, and 4 NGOs reps (3 Bugarian, 1 British) who have been involved with the development of this, or similar projects (see table 2).

Table 2- sample group 2

Name (Gender)	Professional Role (at the time of the interview)	Comment
Todor (M)	Psychologist at Institution X for 10 years Leads on the Baba programme at Institution X	Bulgarian speaking Understanding of English and able to converse in English. Interviewed in Bulgarian using the translator for interpretation.
Ana (F)	Psychologist at the Institution and supports on the Baba programme at 'Institution X' Has worked at Institution X for 1 year (at time of interview). Has experience working in previous roles in Bulgaria and in the UK with children with ASD.	Bulgarian Speaking- Fluent in English having worked as a psychologist in UK for many years. Also acted as the interpreter during the interviews with the Babas and the other staff Interviewed in English
Sonya (F)	Physiotherapist at the institution- working specifically with the Baba programme. Has worked at Institution X for 4 years since qualifying as a physiotherapist.	Bulgarian- does not speak English Interviewed in Bulgarian using the translator for interpretation.
Boyan (M)	Physiotherapist at the institution - working specifically with the Baba programme (Bulgarian- no English).	Bulgarian - does not speak English so interviewed in Bulgarian using the translator for interpretation.
Kalina (F)	Director of a Bulgarian based NGO who leads on similar programmes	(Bulgarian - fluent in English), and who is the Bulgarian lead organisation for the Baba programme Interviewed in English
Susan (F)	Director of the British NGO 1 who leads the Baba programme (with support from the Director of the Bulgarian NGO 1 above)	British Interviewed in English
Elena (F)	Director of a Bulgarian NGO overseeing other baba programmes. Began her work in support of orphanages in 1996, set up NGO in 1999.	(Bulgarian- fluent in English) Interviewed in English
Emil (M)	Assistant to Elena. Has worked alongside and in support of Elena since 1996.	(Bulgarian- fluent in English), Interviewed in English
Elitza (F)	Medical Doctor and New director of Institution X	Bulgarian speaking - No English

Sample Group 3 – the volunteers

The third sample group consisted of five experienced volunteers who have spent time in the institution and have had opportunities to observe the Babas and the children they support. Participants were all contacted through an already existing UK email list, information sheets (see appendix 4) and interview questions (see appendix 2) were sent out and four people were interviewed. All of the volunteers had worked at the institution on at least two occasions (see table 3)

Table 3 -sample group 3

Volunteer	Experience	Language
Kathleen	Former Primary teacher (30 years' experience in schools) Also former resident of Bulgaria with 6 years of experience in institutions/reform. Volunteered in 2010 and other visits.	English speaking Speaks conversational Bulgarian
Bev	Childhood Studies graduate, qualified Children's Nurse Volunteered for 8 weeks in total over 2 year period, since 2010.	English speaking No Bulgarian
Rebecca	Childhood Studies graduate, Post grad children's nursing student Volunteered for 4 weeks in total during one summer visit in 2010.	English speaking No Bulgarian
Jane	Early Years and Disability Studies graduate, Post grad Speech and Language therapy student Volunteered for 14 weeks over a 3 year period, since 2010	English speaking No Bulgarian
Kim	Sociology graduate Volunteered for 4 weeks in total during one summer visit in 2010.	English

With my knowledge of all of the volunteers, having worked alongside all of them, I approached six of them based on the amount of time they had spent in the institutions and also based on their professional areas of expertise as I felt that they would have more to contribute. Of the six who I approached, five were interviewed. In February 2016, through a British contact, I had the opportunity to interview three additional Bulgarian people who I felt would be a rich source of information. Two of these people

lead a well-established NGO based in Sofia (Elena and Emil), one of the first to provide support to children in institutions. They have been providing support to Institution X for many years and are familiar with the Baba programme in institution X as well as similar programmes in other institutions in Bulgaria. The other person was the new Director of Institution X, Elitza, who Elena arranged for me to have a conversation with. I felt that their insight could provide me with more context to the study which I felt was missing. I also felt that their insight into the role of the Baba could add to my existing data collected from the previous 2 episodes of interviewing. These 3 participants were used for a level of 'respondent validation', a level of trustworthiness or authenticity check which adds to the analysis (Silverman, 2013:293). In the interviews which were more conversational in nature as they were carried out in English, I was able to share some of my initial findings for them to comment on.

3.4.4 The Interview

The (flexible) interview guide (appendix 2) was helpful as it gave me a clear script to follow in case the interview did not go as smoothly as I would have hoped. This was particularly important given the obvious language barrier. The interview guide was also translated into Bulgarian and was shown to the Bulgarian participants before the interviews took place.

There is disagreement amongst qualitative researchers about the level of emotion appropriate within the research interview. Ritche and Lewis (2003:163) state that no emotion should be shown from the researcher during the interview. On the other hand, Oakley (1981) notes that, in feminist research the interviewer does not shun openness and emotional engagement. I could not, and did not, claim to be 'detached' from the topic and I was prepared to share my emotions and thoughts in order to develop a more conversational interaction. Denzin and Giardina (2009) describe the interview

as an emotional encounter that brings strangers together in meaningful and intimate ways. Moore and Dunn (1999:196) refer to the 'encroachment of emotionality' in their work and how they could not be as detached as they had assumed when visiting a Romanian orphanage. This emotional component is an essential feature of qualitative research. Gilbert (2001) advises researchers to connect with participants cognitively and emotionally. The etymology of the word 'interview' is to see each other.

During my interviews with the Babas and the volunteers this level of intimacy was most apparent. There were times during the interviews where I had tears in my eyes, often in empathetic response to the Babas' own tears welling in their eyes. The most memorable example and 'critical incident' was during my interview with Baba Violeta who appears to have developed an extremely strong bond with one of her children who she has been with for four years. There were two occasions in the interview where our eyes met and we both became teary and paused for a moment. The relationship and shared understanding was significant here as I understood the profound meaning of the silence (see Clarke 2014:76). An example from the transcript with Baba Violeta highlights this issue:

L - how did you feel when you saw her (the child) for the first time?

BV - Oh, I just felt very sad and was crying, and even when I think about it now, my tears are in my eyes and I just feel sad for her (with tears in her eyes)

Again, later in the interview when asked about the child's future transition from this institution to a different one, there was a very long pause as the Baba's eyes welled up with tears. My eyes also filled up because the Baba looked genuinely upset and worried. Her response, 'I'm worried, very much. If I was younger I could take her with me, I love her', was said with such a genuine look of sadness and concern that I felt very emotional. Whilst I felt that it was appropriate that the Baba could see my own

sadness for this child, I was also aware that I had to 'hold myself together' as this interview was not about me, it was about the Babas and the children. This moment with the Baba challenged me and I felt flooded by the enormity of the situation for this child who, at the age of 13, having experienced extreme developmental harm, and with Down's Syndrome, would likely face a transition to an adult institution very soon. The appalling sense of injustice made me make an immediate conscious and deliberate attempt to emotionally 'detach' myself from the conversation for a brief moment.

I would suggest that being committed to seeing things from the perspectives of the respondents is a necessary aspect of feminist research and not something to avoid, but I would also suggest that it is also important that researchers remain aware of their 'privileged position' within the research relationship. That is, at the same time that researchers are submitting to the respondents' setting and acquiring a variety of peripheral and membership roles, they also retain formal ties to the academic world. Nevertheless, it is important to note that sympathy and empathy can exist in research relationships, connections can be made unexpectedly, and between people who have little in common. Moore and Dunn (2010), used the term 'lines of relating' to refer to the attempts researchers make to identify connections to bring to the research relationship.

The 'lines of relating' between myself and the Babas were predominantly around our shared experiences with particular children. Interviews were marked by many shared smiles, and laughter between myself and the Babas when they were telling stories about their children, especially when their individual characters and their 'funny little ways' were mentioned. For example, when Baba Elisaveta talked about Rumen and says '*you know him*' to me (highlighted in chapter six, pg 212) assuming a level of

shared understanding, I smiled to show recognition and made friendly facial expressions to express *'oh yes, I know his personality!'*

3.4.5 Data Collection Phases

In the original research design, there were only two data collection phases. However, as the work developed four main phases evolved to collect the data:

Phase One involved me travelling to Bulgaria to spend one week in the location of the institution, with daily meetings scheduled during which I carried out the interviews with the Bulgarian Babas and professionals. I combined this with a volunteering trip to different institutions (Y and Z) in an area approximately 56 miles from 'Institution X'. The interviewing phase followed on from ten days of volunteering which served to immerse me back into Bulgarian culture and thinking about institutional life and practices. The volunteering visit was split between a large institution for babies and young children in a very rural and economically poor community (Institution Y), and a day centre for disabled children and their parents which also had a smaller residential sector attached (Institution Z). The day care centre was in the centre of the town. The day care centre introduced me to a different type of services which were beginning to develop in Bulgaria at the time, which offered support for parents of disabled children within the community. Parents were able to attend with their disabled children for play therapy and physiotherapy sessions. Both settings (Institution Y and Z), employed Babas but in a different role to the Babas employed at 'Institution X'.

In these settings (Institution Y and Z) the Babas were employed as carers for the whole group of children. I observed their interactions (as a volunteer informally observing practice, not as a 'researcher') and in this case they didn't appear to have the same level of intimate connection to the children as the Babas in 'Institution X'. I gave thought to these different types of employment of Babas before I travelled to

Institution X to interview them. Phase one of the data collection was the most difficult for me for a number of reasons. I was aware that I was travelling alone from one town in Bulgaria to another which was 56 miles away. I spoke very little Bulgarian and neither of the towns were tourist destinations so the Bulgarians at both bus stations spoke no English. On previous volunteering trips I travelled with groups of other volunteers and often with access to an interpreter. I was very anxious about this when I found myself on a local bus travelling through the Bulgarian countryside for over two hours with no familiarity to where I was. At one point the bus stopped in a very small village for at least twenty minutes and all the other passengers got off. The bus driver stayed on the bus and I felt very vulnerable. I had completed the 'lone worker/travelling safety risk assessment' as part of the university ethics process but it seemed a very 'detached' exercise. I was relieved when the bus started moving again and when I arrived at the outskirts of the town of 'Institution X' I felt relieved when I began to recognise familiar landmarks. I realised this familiarity led me to a great affection for the area and the people here. I felt 'safe' when I got off the bus

I had been to 'Institution X' many times, but this time I was in a very different role. I was slightly anxious that the Babas were used to seeing me there as a volunteer and I wondered how my visit as a researcher might be received and perceived by them. I was aware that 'Institution X' had very recently been on the receiving end of some negative press. The institution was beginning to close its doors to outsiders to prevent further scrutiny, and the new Director had introduced much stricter policies for access, including security cameras in all of the sectors of the institution. Due to these restrictions I was not able to walk freely around the Institution X and I was not allowed to visit Area A. However, I was permitted to interview the Babas as planned and to spend some time with the Babas in the playroom. The interviews took place in the psychologist's private office with an interpreter present. I had intended to interview the Babas in a local hotel near the institution, as I considered that it would be beneficial

to get them away from their place of work where I assumed they could feel relaxed and therefore focused on the interview. I sought advice from the psychologist, who informed me that the Babas would feel more relaxed in the institution. They had agreed to be interviewed, either immediately before or after their 'shift', which meant that it would not interfere too much with the remainder of their day, and would not take time away from the children. Letherby (2003:108) notes 'space and place' as important issues to consider, proposing that 'doing research in a respondent's own place will usually make them feel more in control'. This is especially important to consider when doing research on emotional issues. The room was monitored from the outside by other Babas so that we were not interrupted thus ensuring privacy and confidentiality was maintained. I explained to all of the Babas at the start that they could leave the room immediately if for example they noticed that their child was upset by their absence, or if they themselves felt the need to finish the interview.

Phase Two involved me working alongside the UK based director of the project to formally interview her, to chat informally to gain information about the wider situation in Bulgaria, and to gather notes from documents held by the organisation. I worked alongside her in her home based office in London for a period of two days during which time I also developed materials for use by future volunteers linked to the NGO. I interviewed her 'formally' in the sitting room of her own home without interruptions. I informally spoke with her about the project and made notes.

Phase Three of the data collection involved carrying out a series of interviews with some of the more experienced British volunteers who had observed Babas with the children during their volunteering visits. These interviews were carried out after my interviews with the Babas and staff in Bulgaria. I interviewed some volunteers in my university office and others in locations of their choice. I also heard that the Bulgarian lead for the NGO overseeing the Baba programme, Kalina, was going to be available

for interview in Edinburgh. I travelled to Edinburgh by train and interviewed her in her hotel.

Phase Four involved another visit to Bulgaria much later in the research project to carry out three more interviews and to visit 'Institution X' in an informal capacity to see the changes that had recently been introduced by the new Director. As already mentioned in the discussion of sample groups, the interviews were with 2 members of staff, who work for a well-established Bulgarian NGO which has involvement in the Baba programme in Institution X and a range of other projects with many institutions across Bulgaria. I considered that the opportunity to interview these 2 participants could not be missed as I considered them to have a wealth of experience in this area. The lead NGO contact acted as gatekeeper for me to visit Institution X and to interview the new Director (my 3rd participant of this phase). This last phase was spontaneous and was not planned but it provided me with a useful opportunity to 'try out' some of the themes I had developed during the data analysis process.

3.4.6 Challenges

As previously noted, the aim of the more conversational semi structured interview is that it involves a discussion between equals in a climate of mutual disclosure which contributes to the social production of shared meanings and richer accounts (Ellis and Berger, 2001). I realised early on in the initial data collection phase that this was more problematic than I had anticipated due to the language barrier and the perceived 'power' imbalance especially between myself and the Babas. It was apparent to me that during the interviews, whilst the Babas were forthcoming in talking about their children, they were not quite as animated as our previous informal conversations had been during my past visits as a volunteer. I sensed that they perceived me differently this time in my role as 'researcher' from a UK university. The psychologist kept referring to me as a professor which on one hand was amusing although I did not wish

to assume such a 'grand' status. This was far removed from how I had previously presented myself simply as a volunteer with grandchildren of my own back home. I also wondered afterwards whether their reservation was because the interviews were being recorded. It was interesting that some Bulgarian friends told me that one of the lasting legacies of communism was that Bulgarian people are wary of being 'watched' and 'listened to'. Had I considered this earlier I might have been able to appreciate this more and perhaps ask the translator to really stress the confidentiality aspects even more than I had done. The interviews with the English speaking Bulgarian professionals and the UK volunteers were very straight forward and more free flowing and conversational in nature.

The interviews with the Babas were translated on the spot; I asked the questions in English, the translator then asked it in Bulgarian, the participant answered in Bulgarian which the translator then repeated to me in English. I made rough notes in my notepad as she spoke so that I could recall significant points to 'probe' where appropriate, and also to keep a record of the interviews to compare with the fully transcribed interviews which would be translated by a different translator at a later date. I also tried to capture some of the non-verbal communications in my notes. Before starting the interviews I believed that this on the spot translation would allow me the flexibility to 'follow up ideas, probe responses and investigate motives and feelings' (Bell, 2005:157) in my role as 'skilled interviewer'. This proved much more difficult than I had anticipated. As the interviews were taking place, I was not sure that the translator was being 'full' in her translations, so I found it difficult to 'probe' further. Papadopoulos (2006) suggests that getting the MP3 files retranslated at a later date, back-translation ensures accuracy of translation and ensures that crucial meanings are not missed. I therefore asked a Bulgarian friend, who had completed her own PhD in the UK and who had worked alongside me on one of the volunteering project, to do another translation for me. Her translation when compared with my own notes did add more detail. She also

commented on some of the cultural interpretations which helped to add to my understanding.

When I had the recordings fully transcribed and translated, I compared them with the notes that I had taken and realised when reading the participant's responses that the original translator had not translated verbatim for me. Upon reading some of the responses in the full transcripts, I felt frustrated that I had not had the opportunity to follow up the way I would have done had the interviews been conducted in English, but I also felt that the data I had collected still offered rich insights.

3.4.7 Data Analysis

In engaging with this research project my intention throughout has been to tell a 'well substantiated story' and to reveal what matters most (MacNaughton, 2010). In relation to this research it was therefore imperative to sift through the data during a number of stages and over a long period of time, in order to address the overall research aim. Whilst I was excited and eager about this phase I was aware that the data sorting and analysis period can be overwhelming unless a systematic approach is adopted. Denscombe (2010:295) notes that

'qualitative data analysis is the process of bringing order, structure and interpretation to the mass of collected data. It's a messy, ambiguous, time-consuming, creative and fascinating process. It does not proceed in a linear fashion: it is not neat'.

A large amount of data was generated during the course of this study which included sound files, transcribed interviews, field notes and limited documents held by the organisation. This 'totality' of data, or data *corpus*, was not included in the final analysis, rather the final data set was a result of refining and pruning of data items as the study developed. The data analysis was an iterative process in different stages and it became evident that some were no longer useful in addressing the research aims. For example, the documents held by the organisation were not included in the

final data set, only the interview data and some of the personal notes that British volunteers had shared with me. The final data set included in the analysis consisted primarily of the interview data from all twenty participants. Other items had however been useful in developing the context setting. Having read through all of the transcripts numerous times to familiarise myself with the data I was aware of many potential themes occurring. Whilst in agreement with Denscombe (2010) that data analysis is not a neat, linear process, but driven by my desire to make the task as manageable and organised as possible, I opted to adapt and use the six stage thematic analysis proposed by Braun and Clarke (2006:88).

Thematic analysis is 'a method for identifying, analysis and reporting patterns and themes within the data' (Braun and Clarke, 2006:82) offering flexibility as well as a methodologically sound 'recipe' for qualitative analysis. This approach is in keeping with the social constructivist approach of this study as it stresses the need for the researcher to make their assumptions explicit, requiring the researcher to explain the 'how' of the analysis rather than presenting the 'themes' as if they have 'emerged' unbiasedly from the data set. This will be discussed in more detail later.

Before reaching the 'formal' stage of data analysis, I had been immersed in an 'informal' process of data analysis which was on-going throughout data collection phases and beyond. I was aware that when carrying out the first interviews I was thinking analytically both during and after each interview. I pondered each interview in relation to my own understanding and previous experiences at the institution and I applied my own informal analysis to what I was hearing both during the interviews and when reading through the transcripts afterwards. I also had developed a theoretical framework from chapter two. My data analysis journey is outlined below although I must stress it was not as linear as this outline presents. The 6 stage approach was therefore only used as a flexible framework.

Stage 1 Familiarising with the data

The importance of listening over and over again to the interview to become familiar with the data is vital. As some of my interviews were in Bulgarian this was difficult to do, but I did read through all of the transcripts many times before embarking on the 'formal' analysis process.

Stage 2 Transcription of verbal data in verbatim and checking against audio recordings

The interviews in English were transcribed by me but an interpreter was used to translate and transcribe the Bulgarian interviews. Issues associated with using a translator have been highlighted in the previous section. The translator/transcriber was very thorough in her translations and made repeated checks against audio recordings, also checking with myself to ensure accuracy. When reading the translated transcripts I checked them against the written notes that I made during each interview to ensure as full a translation as possible. My notes included comments which also captured some of the emotional aspects of the interview.

Stage 3 Generating initial codes. Here codes relate to the most basic segment or element of the raw data that can be accessed in a meaningful way regarding the phenomena

I stored data on my password protected lap top, but found it less complicated to sift through the paper copies of everything, especially in the initial coding phase. First phase data analysis, or generation of initial codes was therefore coded by use of coloured pens, paper, post it notes and large sheets of paper. I printed out the transcripts, read through them and highlighted segments of text identifying broad codes. I then recorded each code in a separate list, noting where these had occurred in each interview.

I had spoken with my supervisors and other PhD students who recommended using computer based software designed to assist with qualitative research such as NVivo 10 which is currently used at Northumbria University and I was initially keen to try it out, however, practicalities led to beginning the coding before I could access the NVivo 10 training session and once I found myself immersed in a straightforward, manual coding technique, I decided to continue with this process. This method of working with hard copies also appealed to my preferred 'visual' learning style as I could see the data, highlight sections of it visually using coloured pens as well as cutting up sections and sticking them onto different posters that developed around the themes. During this stage I was confident that my own method was rigorous and it appealed to me because it allowed me to feel ownership of the analysis. Macnaughton (2010) notes the dangers of analysis being led by what the computer programme can do which can lead to a pattern of analysis being too rigid and narrow,

Having read through all of the interviews to familiarise myself with the content I became aware of the amount of data that I needed to sort into manageable and meaningful themes, I decided to use a simple technique of reading through the two interviews which provided the most detailed information, noting the main themes that stood out. These were the interviews provided by the British NGO representative, Susan and the psychologist, Todor. I colour coded these and used them as a starting point for the remaining transcripts.

As I read through each transcript, trying to be as 'open minded' as possible, I could not completely empty my mind of the theoretical perspectives and literature that had framed the study, therefore the initial codes and themes that were 'emerging' were undeniably linked to my previous knowledge and understanding of the subject area. I was slightly confused at this stage, especially in my position as a fairly novice researcher, about whether I should be allowing my mind to wander into this already

explored territory of knowledge or whether I should try to remain impartial and open to any other new themes that might emerge. I was uncomfortable with the idea that themes would 'emerge' from nowhere as if I, in my role as researcher, were passive in the process. My chosen approach of ongoing embedded reflexivity was in appreciation of this issue with the understanding from the beginning that I would not remain unbiased and detached.

During this stage there was obvious overlap as in my attempt to be as 'free' as possible, I listed the first thoughts that entered my head as I read. Having completed an extensive amount of reading around the subject in order to write a thorough literature review, I was aware of some of the key aspects that might eventually be included. For example, as I was reading through the transcripts I couldn't help but reflect about how the findings might look alongside the features of the 'total institution' as identified by Goffman (1961). Where Babas mentioned intimate aspects of their role with the children, I did reflect on the contrast between this and the anonymity of collective life in Goffman's account. Likewise, I could not help considering some of the child development perspectives, particularly the emphasis on attachments (Bowlby, 1951) and responsive caregiving when Babas described the excited screams of anticipation from children at the beginning of each session when their Baba arrived.

I was reassured by the words of Ely et al (1997:205) who state that 'if themes 'reside' anywhere they reside in our heads from our thinking about our data and creating links as we understand them'. I therefore accepted that many of the themes would undoubtedly sit within areas that I had researched for the literature framework, but that I would also try to be mindful that other key issues might develop. Following this line of reasoning my analysis was both 'theory led' and 'data driven' (Macnaughton, 2010).

My first attempt at sorting through and analysing data produced the following 22 codes:

1. Baba's 'general' role description
2. physical care e.g. smell and appearance, feeding routines
3. attachment and bonding
4. language development and communication
5. identity and developing sense of self
6. Babas understanding each child's needs, likes and dislikes
7. 'knowing' the child as a 'unique' person
8. being 'held in mind' when apart
9. physical development and exploration
10. general life in the institution
11. life for the child in the institution- 'before' the Baba
12. creating a 'family' around the child
13. creating a 'team' around the child
14. gains for the Baba
15. 'reciprocity' in attachments
16. policy issues and 'what next?' for the child
17. interactions from Baba to child
18. building resistance and resilience
19. attitudes towards disability
20. attitudes towards 'orphans'
21. 'human touch'
22. Baba as 'advocate' for the child
23. challenges to the programme
24. political context

Having done this I was aware that emerging themes focused around the role of the Babas as a protective factor against the negative impact of institutional life for the children.

Stages 4 and 5 *Searching for themes, and reviewing themes.* Here a collection of candidate themes and subthemes are identified and all extracts of data are coded in relation to them. My initial thoughts on the emerging themes were the importance of the Babas in providing unconditional care and support to each child, and the Babas' enjoyment and sense of pride in their caregiving role. Additionally, the level of emotion in their answers demonstrated the obvious attachment that they felt to 'their' children. Overwhelmingly, what stood out most prominently from interviews with Babas, professionals and volunteers was how anonymous, stark, harsh and lonely the children's lives were before the input of the Babas.

I began to realise that some of the themes were overwhelmingly more significant than some others. For example, I had not anticipated how often the word 'love' would be mentioned by the Babas in talking about 'their' children. It was highly significant to me that often the Babas referred to the child as 'my' child. I began to think about the various dimensions of caregiving identified in the literature and how the main themes seemed to reflect some of these, all of which overwhelmingly relate to the importance of attachment relationships. As I was reading through all of the translated transcripts, I became concerned that the words themselves did not reflect the whole conversation or context specifically as much of the important non-verbal communications that had taken place were not noted. I recalled that during the interviews I had written some rough translations 'on the spot' as well as some notes about the non-verbal communication coming from each participant. I revisited my notebook and used this alongside each transcript to remind myself of the emotional context of each interview. The Babas had been particularly expressive in their non-verbal communications

during the interviews, often with laughter, proud smiles and head nods and shakes (a typical Bulgarian non-verbal 'yes' and no), and often with tears and looks of great sadness and concern. As I read their words again and again, I found myself recalling the emotions present in each interview. I have therefore, at times, included some of the non- verbal gestures alongside the quotes.

Emerging Themes

I sorted the initial codes into fewer themes and into a more meaningful sequence. I felt it was important to present a flavour of what life was like for the children in the institutions before they had a Baba. For me, this was particularly important because all of the respondents mentioned aspects of institutional life for the children many times throughout their interviews, therefore, they must have felt it was worthy of inclusion. I felt that this warranted a clear section at the beginning which would 'set the context' from which to explore the Babas' role. From here, I have presented further themes using the Bronfenbrenner (1979) concept of the child developing as their world becomes increasingly larger and more complex. I was also involved with defining and naming the themes. This process is outlined in the table 4 below.

Stage 6 of Braun and Clarke's (2006) model is the writing up of the report.

Table 4- analysis and developing themes

Summary of coding, developing and reviewing themes		
Initial codes (stage 3)	Developing themes (stage 4)	Reviewing themes (stage 5)
Baba's role physical care e.g. smell and appearance, feeding routines attachment and bonding language development and communication identity and developing sense of self Babas understanding each child's needs, likes and dislikes 'knowing' the child as a 'unique' person being 'held in mind' when apart physical development and exploration general life in the institution life for the child in the institution- 'before' the Baba creating a 'family' around the child creating a 'team' around the child gains for the Baba and 'reciprocity' in attachments policy issues and 'what next?' for the child interactions from Baba to child building resistance and resilience attitudes towards disability attitudes towards 'orphans' 'human touch' Baba as 'advocate' for the child Challenges to the programme	Institutional life before having a Baba Baba 'role' ie. what they do Attachment and belonging Developing a positive identity A secure base from which to explore the world Being part of the wider community/citizenship	Linked more to Goffman's 'total institution' Reviewing and categorising around 'features' of the total institution. Minimising stigma Minimising distance Increasing visibility Supporting development of self, agency, resilience and recovery

3.5 Conclusion

I have positioned myself as a feminist researcher, informed by disability and childhood studies research, straddling both inside and outsider positions. In terms of the area of study I am a foreign, non-disabled adult which distances me from the participants of the research. However, I did find 'lines of relating' to the participants which I feel worked well, and I believe I have continued to reflect effectively on this. In terms of the most suitable approaches a qualitative research methodology was chosen as the most 'fit for purpose' and best suited to my own philosophical, values, professional heritage and identity. A rigorous thematic analysis was applied that was both inductive and theoretically driven. The next chapters four, five and six present the findings from the interviews in terms of themes developed during data analysis process outlined in this chapter. Discussion will be integrated throughout the findings chapters. In chapter seven conclusions are presented and discussed in relation to further themes as outlined in table 4 above.

Chapter Four

Establishing the Bulgarian Context

4.1 Introduction

Chapters four, five and six both follow and expand upon the themes presented in the data analysis table presented in chapter three. This chapter provides an introduction to the presentation of the themes emerging from the data. It offers an overview of research participants' understanding of the Bulgarian context regarding institutional care for children and an analysis of the features of Institution X in relation to Goffman's (1963) concept of the 'total institution'. This serves as a foundation from which to explore the Babas' role in depth, adding to the initial understanding developed in chapter two.

The inclusion of this contextual back drop aligns with the conceptual approach of Childhood Studies and the ecological approach to children's development. Both have at their core the desire to understand a child's developmental experience, seeing it as inseparable from the complexities of the social and cultural processes and values which they are born into (UNICEF, 2006; Bronfenbrenner, 1979, 1986; Packer, 2017). Additionally, as Goffman's (1961) concept of the 'total institution' is core to this analysis, as a frame from which to understand the children's experiences in relation to de-institutionalisation, it was crucial to create a picture of what life was like in the institution before the Baba project. Whilst the main focus of chapters five and six is the everyday 'micro' (system) experiences of the children, an understanding of the wider macro context as presented here, adds weight to the analysis, as these factors are inseparable from children's lived experiences (Leonard, 2017).

The presentation of the themes emerging from the analysis of the data contributes, in this and the following chapters, to the development of a response to the overall research focus. This focus, as noted elsewhere in this thesis, is about exploring the role of the Babas in the children's lives and understanding their potential to contribute

towards the de-institutionalisation of these children whilst they remain in the institution.

The findings presented and discussed in chapters five and six give critical insight into the role of the Baba as perceived by all participants, and contain a more detailed analysis of the Babas' role broken down into the distinct aspects of their caregiving practices and interactions with the children. This analysis allows me to indicate how the Babas' practices may be seen as having developed into an alternative model of 'caregiving' for the children in Institution X. This is further analysed in relation to whether the Babas have potential to contribute to the 'de-institutionalisation' of the children in Institution X.

In presenting participants' responses it is important to mention that some of the language used by participants, particularly those from Bulgaria, appears to be in contrast to a social model, or, an inclusive approach to disability. I believe this to reflect an important cultural difference around understandings of disability, and a translation issue, and I have therefore left these terms as they were spoken. During the interview process I also became aware that when I used the term institution, some of the Bulgarian respondents became confused, as they used the term orphanage. To remove this confusion on the part of participants, especially given that I worked through translators, I used the term 'orphanage' myself in some of the interviews and have therefore left the term in the findings presented here. Whilst this chapter offers the findings, useful information regarding participants names and roles can be found in chapter three on pages 120 and 121.

4.2. Carrying the Load of Old Times

The interviews with NGO representatives and the most experienced of the participating psychologists began with questions aiming to seek their understanding

of the reasons why there are, and have been, so many children in large scale institutions in Bulgaria and what institutional life is like for the children. The conversational and free flowing nature of these interviews (conducted in English with English speaking Bulgarian participants) allowed exploration of social, historical, political and cultural aspects of childcare practices. This further contributed to my understanding of the factors that led to the emphasis in Bulgaria on large scale residential facilities for children without parental care, including children with impairments. It is noteworthy that a significantly high proportion of children in Institution X are from the Roma communities, a point that is worthy of further attention elsewhere but is not within the scope of this thesis.

The main contributors to this introductory theme around 'context setting' were the Bulgarian NGO representatives Elena, Emil and Kalina, and the lead Bulgarian psychologist Todor, all of whom have always lived in Bulgaria and have extensive experience working across the country over many years. In their professional roles they all provide support to a range of projects including the orphanages and Baba programmes, so they are therefore familiar with the de-institutionalisation strategy and other policy implementations in Bulgaria.

All these participants' responses reiterated that the children in these institutions are not simply 'abandoned' by uncaring parents. When asked 'why do you think Bulgaria has so many children in orphanages?' the participants' responses mirrored explanations outlined in chapter two, including; some deeply embedded negative attitudes around disability; a lack of support for families with a disabled child; Bulgaria's communist past which they argued still fosters a familial ideology promoting institutional care and undermining parental care; and Bulgaria's very recent and current position as a country struggling with political and economic transition (Carter, 2005; UNICEF, 2006; UNESCO, 2010; Rassel and Smirnova, 2014).

Statistics suggest that the use of institutional care in Bulgaria increased significantly during the socialist period, and continued to increase during the years following the political changes in 1989 to a democratic model (Ivanova and Bogdanov, 2013; UNICEF, 2007; UNICEF, 2010). Reports confirm that despite being an expensive form of care, institutional care tends to be used more readily in poorer countries and those experiencing economic transition (Browne, 2009; Nelson et al, 2014). This was reflected in Kalina's account where the impact of Bulgaria's recent transition from socialism was at the forefront. For instance, she commented that:

for many reasons Bulgaria is a very poor country, umm, we have never got rich, even now we are part of the European community, now we are a democracy but still the communists are very much into everything, and kind of, the population cannot normally breathe and develop for a second... So often I think the main reason is economical.

Kalina, NGO

Elena also noted the significance of the difficult economic situation in Bulgaria, which was woven through her explanation of how she first became involved in her NGO work with orphanages:

It's been a long time ago, in 1996 Bulgaria was on the verge of civil war, it was most political, the situation was very, very bad and unstable, and the people went out on the streets and protested the situation, and eventually the situation grew very, very bad and there was absolutely nothing.

Elena, NGO

I asked Elena about conditions in the orphanages during the communist period, pre-1989, but she was unable to comment about them from experience, because, as she said, '*they were hidden away*' and she was not really aware of them other than hearing about friends who had adopted children from them. Nevertheless, her account did shed light on the damaging impact of the political and economic transition for the children living in orphanages during that critical period from late 1980s and into the early 1990s:

the errr tragedy started with the change, the start of the transitional period, maybe starting a year or two before that, these are only guesses... I don't really know how much the government took care of these children during this period of socialism, but in years, when it was a transitional period for Bulgaria, somehow people were focusing on adopting socialist plans into a capitalist kind of country, so it was hard for everybody, so orphanages was the last problem we had, and because of that, as I said, it was very hard for old Bulgarian people to adapt to the situation, there was a lot of ups and downs for a lot of people everywhere, factories and plants were closed down, thousands of people lost their jobs, people could not adapt to the new requirements, it was very very err difficult situation and it lasted until the last of the nineties, and this last ten year period, the situation in those orphanages worsened.

Elena, NGO

Kathleen, who had lived in Bulgaria during this period and worked alongside Elena in providing support and resources to the institutions struggling to provide even the basics for children, recalled how desperate the situation had become:

I used to get phone calls from directors of orphanages saying that they hadn't had their monthly allowances for the children at the orphanages... and at one stage the director of the orphanage said that the only food that they had was sugar and they were having to boil it and caramelise it to give to the children to lick it.

Kathleen, Vol

Emil's explanation in the extract below alludes to a culturally embedded practice stemming from the communist ideology of children belonging to the state:

E: at that time everything belonged to the state

L: even the children?

E: more or less even the children. Of course, when they have parents they belong to their parents but in the same times (pause for thought) in the same times, they belonged to the state. If they were boys they went to the army, the army would count them like soldiers. Or, they would count them like workers for the industry, and it's like, err, anyway on that time for us it was impossible to leave the country and start your life somewhere.

Emil, NGO

He referred to this as 'carrying the load of the old time, when it was easy to leave your child in an institution', thus concurring with what was identified in chapter two (Everychild, 2005; Walker 2011). Speaking specifically about disabled children he extended this explanation, reflecting the comments from Elena about orphanages being hidden, stating that:

the kids in socialist times were hidden, it was a shame for our communist country that we have uhm deviated persons, no, we were perfect persons, we were communist persons and we were only healthy. That's why handicapped kids, not even kids, **all** handicapped people, were hidden in the middle, in the middle of nowhere, down the road another 5 kilometres and there is the orphanage. And that is the problem with people with deviations now, as society is not familiar to meet them on the streets, even me, I am not so old but even in my childhood very rarely I see someone in a wheelchair.

Emil, NGO

Elena's comments further reinforced Emil's regarding disability and stigma. Noting the culture of shame around disability associated with the soviet legacy, she explained that children with impairments still pose a 'delicate situation' for Bulgarian families. She added:

also you know, uhm, it is considered, once upon a time, during socialism and after, disabled child was considered like a stigma you know, so many parents hid their children and never took their children out their houses, especially in small villages and towns...

Elena, NGO

This sense of shame, silence and the hiding of children with impairments, as experienced by families was illustrated further when she explained that on the opening day of their charity's first day centre for disabled children in a small village in the North East of Bulgaria:

all of a sudden it turned out that there were so many disabled children that there was not enough places for all the children...

Elena, NGO

Medical model understandings of disability and accompanying practices were evident in comments in interview. This also helps to explain the over-representation of disabled children in institutional care in Bulgaria. Emil's account stresses the powerful role of medical professionals in reinforcing the segregation of children with impairments from their families by actively encouraging them to give up their babies at birth. He told me that:

It's not a secret, maybe they gave up at birth a retarded child or deviations, they were pressed from medical professionals, say, doctors, nurses, say, not so pressed, but simply they explained 'oh come on you can leave this child in the institution, you can make a new one, it's no problem. If you get rid of it, it will be easier and better for you' ... it is very difficult to care for such a child and that's why it was easy for parents to leave their child in these institutions.

Emil, NGO

Further, Elena provided an example of how medical professionals held power and influenced decisions made about the future of a specific child who was born with Down's Syndrome. In her account the doctors and grandparents acted without the mother's agreement:

when the government started planning this de-institutionalisation they wrote letters to all parents, to all mothers of children who were all left in these institutions, the idea was that those who still have live parents, to let the children be integrated into their families, and what was the surprise of the family when they received a letter to go pick up their child?, this Down Syndrome child, when they were told when they gave birth, that their child died immediately after the birth..., and how it happened?, both grandparents of the child decided that it was a shame to have a disabled child and it would be very difficult for the parents to take care of the child. They decided, and arranged with the doctors to leave the child behind and asked the doctors to tell the mother that the child died immediately after birth... I can tell you lots of stories like this of when the mothers were not aware their children had been given away because of their disabilities.

Elena, NGO

What this additionally indicates is that some parents may have been unaware that their child was still alive. In a similar vein, Todor's explanation also refers to disability

with regard to individual circumstances, but not in relation to stigma or shame. Instead, he demonstrates awareness of the complexity of cases, also noting the intersectional nature of poverty and disability, which is heightened during transitional economic periods (Browne, 2009, Mulheir, 2012). He explained that:

Actually, it turns out that they do not just abandon them, these families cannot take care of child with disabilities. Various reasons exist and each case is individual so for us to conclude is difficult. But the fact is that the families try to find the convenient place for the child rather than to abandon it. What I want to say is that they are giving another life to the child where they believe care will be better, for this reason they come to the institutions and give their child.

Todor, NGO

Todor's explanation confirms that the children are 'social orphans'. They are not simply 'abandoned' by uncaring parents, but placed in the 'care' of the state by families who appear to have limited options if they are to ensure the survival of their child, themselves and other family members. Like Emil, Todor's understanding also suggests this practice is embedded within hegemonic discourses around disability and the role of the family and state during the communist period, something which continues to linger despite political transition.

4.3 Cots, Cradles and Cages

Establishing whether Institution X can be seen as a 'total institution' is critical in relation to the primary aim of the research project. Once the construction of the institution has been explored the work can then move on to analysing how the Baba relates to the child in this context. To open this section I include here a poem written by one of the volunteers after the volunteering visit of one month during 2010. The poem captures many aspects of life in Institution X, and I present it as a useful starting point in establishing what life was like for the children in institution X:

‘Cots, Cradles, and Cages’ written by Kim (Volunteer)

Expressionless faces peering out from within white cells

Housing nothing but bones and tears

Falling from pain filled eyes

Over fragile translucent skin

Lost within an eerie silence

Of missing voices and missing memories

Of a life of happiness and peace

Piercing cries echo off bare white walls

And cold tiled floors

Reverberating off the bars

Of cots, cradles, and cages

Stuck in the past

In a memory of shattered glass

Like stars reflecting a ghost

Of a life that could have been

Paralysed with fear, Afraid to move

Struggling even to breathe

Feeling no love or affection

And receiving no attention

Restrained within cloth

Despite its central position in a large town, the children in Area A (the upper floors of Institute X in which children with disabilities are placed) are invisible, in social isolation. This links with Goffman’s definition, which includes an element regarding ‘restricted contact with the world outside the walls’ (Goffman, 1961:18) something still

apparent when participants shared their first impressions, despite cultural shifts linked with social change. This isolation from the wider community was reflected in Susan's account of the difficulties she faced when trying to recruit Babas the first time. She noted that they seemed keen to be involved until they saw the children:

Out of the first group of 20 who came for interview, recruitment was impossible due to the nature of conditions in the institution... yeah, I mean one woman actually left the room with her hand over her mouth like she was going to be sick and the others you know looked painfully embarrassed and what really shook me is that none of them went to touch the children, not one, they kind of looked at them and observed them and then walked out.

Susan, NGO

The isolation of the children in Area A of institution X was also recognised by one of the psychologists, Todor, who noted that for many years of working there, he had not been able to gain access to the top floor (Area A) which was accessed only by 'medical staff'. He had only become aware of the conditions in this part of the institution when he became involved in developing the Baba programme. His account illuminates the point that not only are disabled children segregated off from the wider society by being placed in the institution, but they are also subject to segregating practices within the institution. He commented that:

the system divides the children in healthy children and children with ill condition, and therefore the focus is on the healthy children, and little for the children with illnesses. And for the first time, this project was focused on the children with disabilities.

Todor, Psychologist

For many of the research participants, and for myself, the part of the interview where participants were asked to recall their initial visits and their feelings when they first met the children were emotionally challenging. Their accounts conjured up a very bleak and depressing picture of life in Institution X much of which was in line with Goffman's analysis. Some of the participants appeared visibly upset and struggled to

contain their emotions when recounting their initial meeting with the children and observing institutional life for the first time.

Participants' comments focused primarily on the shock they felt at the physical appearance of the children, the emotional sterility of the environment, the lack of attention paid to the individual needs of each child, and the realisation that this was an established organisational culture which appeared to condone and reinforce unsatisfactory caregiving practices. This appeared in direct contrast to the children's needs (Save the Children, 2009). In commenting generally on institutional life, some of the participants likened Institution X to other facilities incorporated in Goffman's definition of the 'total institution' (Goffman 1963). Some participants observed its similarity to a prison (Kalina and Rebecca), an army building with army routines (Emil), and like myself (in appendix 1) a concentration camp (Susan and Kim). One of the volunteers, Kim, had also reflected on the same incident in the form of another poem that she shared with me:

Written on his skin scribed in pen
His name, soon to disappear
Like the boy, neglected and abandoned
His life rubbed out
His identity forgotten
A number now
A non-being amongst the masses
Defined by this stamp
A prisoner now in a childhood concentration camp

The smells and sounds of the institution were often recalled as the primary memory and one which provoked a visceral response. Kim captured this in her personal memoirs of volunteering in Institution X:

I will start with the smell. It is a smell that makes your eyes water and your nose burn. It is salty. It is stale. It is hot and moist and seems to be full of the sterility of urine. It is a smell that hits you in the chest like an unexpected punch. It is a smell that reeks of injustice and screams of neglect. Now imagine a sound. One that is at first silent. It is a hollow silence that moves through the orphanage grounds like a ghost... It is a silence that contradicts the magnitude of the building with its row upon row of corridors, and its row upon row of cribs. It is a silence that is slowly penetrated by a quiet and constant thudding – the rhythmic movement of heads banging against walls and bars.

Kim, Vol

Like visitors to similar orphanages in Romania who noted the 'eerie silence' (Nelson et al, 2014; Brown and Webb, 2005; Moore and Dunn, 1999) participants were disturbed by the lack of noise that would typically be expected from large groups of young children. Susan (NGO rep), who had visited many institutions, compared them with Institution X noting:

I had been to 'Institution Y' which was horrific, but that was older children, and it was just barbaric, and I would actually say that was the nearest you could get to a concentration camp. It was so inhumane but the children were older, and while the children were in a bad state nothing prepared me for Institution X because they were so little and helpless and just so chronically sad... and the silence of Institution X was something that shook me, whereas the others were loud like a madhouse, it (institution X) was just a mortuary, it really was.

Susan, NGO

Jane became notably tearful when she recalled her first volunteering visit in 2010, recalling the silence before moving on to other strong memories which capture the presence of some totalising features of batch living in Institution X. The following extract from our conversation illustrates this:

J: I remember in sector C (the babies), there was just silence, because they'd sort of learnt that nobody would come for them if they cried. The only sound that you could hear was the occasional child banging their head against a wall or a crib and it was just distressing.

L: Mmhm (pause while Jane composes her thoughts- shared moment of understanding and both momentarily tearful)

J: When I was in my first year, I remember Area A upstairs, I kind of took, because of my disability background, I really took a big interest in that. I remember the children had had bones broken, but they'd not been set properly, they were malnourished, they just lay in cots all day, lying in their own excrements. I remember just walking in, with the smell, the conditions the children were living in, and the conditions the children were in...

L: Mhm. (another short pause to allow for Jane's emotional composure)

J: Watching meal times and things, seeing how they were either fed as fast as possible or given a bottle with the teat cut off and left on the side of the crib. If the baby knocked the bottle off with their heads there'd be milk on the floor, just left there and they wouldn't get any more. I just don't know how to explain it because I was so, I think, disgusted and upset by it. I don't think it's anything I'll ever forget.

The overwhelming and unfamiliar smell was noted in my diary entry presented in Chapter one of this thesis, as one of the most vivid memories for me. It was also highlighted by other volunteers and visitors to the institution. Kathleen reminded me of a volunteer vomiting out of a window as a result of being overwhelmed by the smell in Area A, and Kim's account of her first visit to Area A captures not only the smell, but the loneliness of life there for the children. She wrote:

As soon as the door to Area A opened a stench greater than any other filled our noses. It is hard to explain the smell. It was as if vomit had been sewn into the fabric of sheets, trapped between the small fibres. It was exacerbated by the smell of stale urine and faeces that had settled into the walls and floors, and that had been absorbed by the wooden frames of cribs. What I remember most about entering the second ward in 'Area A' was a small contorted body of a child. The child was sitting up, bending slightly forward, her head dropped back, and her legs spread in opposite directions as if doing the splits. She was staring up at the door. It was as if she had been sitting in that position for years, watching the door, and waiting for someone to enter it.

Kim, Vol

Some of the Babas' reflections on seeing the children and their living conditions for the first time suggest that they were unaware of such conditions, as life behind the

walls of Institution X had been invisible to the local community, something that also suggests aspects of Goffman's 'total institution'. In trying to establish a picture of life in the institution for the children before they had Babas, I asked two questions of the Babas; 'how did you feel when you met child for the first time?' And 'what was life like in the institution for child before they had a Baba'? In answering these questions, some Babas paused to consider how they would respond, and then responded with tears in their eyes. For some, this sadness was evident when I asked them to recollect how they felt when they first met the child they would be caring for, which suggests that the memory of seeing 'their' child for the first time was a painful one etched in their minds. Baba Margarita, with tears in her eyes, expressed her initial feelings about Dida, one of 'her' children:

Aww! I was traumatised the very first time. And there was someone who told me that most of the people feel the same way... However, I needed some time to accept it and to realise I am helpful to these children.

Baba Margarita

As well as pausing to compose her own emotions, Baba Margarita's hesitance also appeared to be an attempt to protect me from what I was about to hear. Before she started to describe the child to me, she first turned to the psychologist (who was acting as a translator) and asked, 'does Lindey know this child?' When I smiled and showed recognition of the child's name, it was as though this acted as a signal that I was adequately prepared to hear what she was about to say. She continued with the following description of Dida (aged 13 years 6 months), when she first met her:

I first saw her in the bed in a strange position, like a little baby frog. I couldn't understand where her legs are and where her arms are. But then I looked at her eyes, and I saw some kind of desire, I saw she needs help, this little kid. I am talking about the expression of her face, I was thinking 'this child needs help'.

Baba Margarita

She elaborated further when asked about Dida's life before she had a Baba:

Oh! I believe her life was very much constrained. She never got out of the bed, and she was until this moment eating with a bottle. The bottle was leaning against the bed and was not even held by anyone.

Baba Margarita

Her opinion about Dida's earlier life reflects the presence of features of the 'total institution' including depersonalisation, a rigid feeding routine and lack of emotional responsiveness to individual needs. As is the case in a 'total institution', caregiving practices in Institution X appear to be focussed around the organisational routine rather than the individual needs of the children, and the care staff were reported as being detached and uninvolved. In chapter two I noted the tendency for organisational cultures to also have a negative and demoralising affect on those working there, which leads to practices that can be detached, impersonal and abusive (Guishard-Pine et al, 2017) and this was evident in comments from participants. Some of the research participants appeared to be critical of the staff for being detached from the children, whilst others recognised that the staff were also institutionalised. The NGO, volunteer and psychologist participants' accounts focused on this particular element of staff behaviour more than any other. For example, this detachment was noted by one of the volunteers, who described a situation where:

The staff usually were sitting about out in the kitchens. They weren't necessarily with the children, unless it was feeding time and sorting out the feed, but you never really saw them with the children.

Rebecca, Vol

The detached attitude of some staff towards the children was also commented on by Ana, one of the psychologists:

and the staff are (pause for thought)...it depends on the person but the way the staff handle the children is never to acknowledge their needs and their reactions but to do what their obligations are and finish as quickly as possible (pause for thought) which makes it very harsh on the children.

Ana, psychologist

In contrast, not one of the the Babas offered a criticism towards the employed care staff in Institution X. Even when they spoke about the poor conditions the children had to exist in they tended to focus more on organisational flaws in practice rather than identifying individuals or staff attitudes as problematic. In an article entitled 'The Violence of Disablism', Goodley and Runswick Cole (2011) remind us that violence lies in systems and structures. They state that,

'to tackle this violence means not simply targeting those few 'evil souls' responsible for hate crimes against disabled people but deconstructing and reforming the very cultural norms that legitimise violence against disabled people in the first place' (p.614)

The Babas' lack of apportioning blame to the caregiving staff may reflect their own deeper cultural understanding linked to history, and their own realisation that the violence is more embedded into the cultural context. Nelson et al (2014) noted that caregivers received no formal training and cared for large groups of children and that care was given in a detached manner. Mulheir (2011) also notes that such abuse is not universal and that 'abusive' does not apply to all staff.

4.4 Summary and discussion of chapter four.

In chapter two I presented literature from a variety of academic sources which concluded wholeheartedly that institutional care for children, particularly disabled children, is harmful to their development. Caregiving practices in most institutions, due to the very nature of institutional life, are not conducive to promoting the intimate caregiving relationships and appropriate opportunities for exploration and stimulation needed by all children. In order to demonstrate this, I used a synthesis of Goffman's

(1961) analysis of the 'total institution' with child development theory to investigate 'why' the institution is so harmful for children. The key finding from this is that institutional care generally struggles to replicate the domains of caregiving typically provided in family contexts (Bornstein and Putnick, 2012; Schofield and Beek, 2005; WHO, 2004).

Overwhelmingly, the accounts from all of the participants, suggest that conditions in Institution X both before and during the initial stages of the Baba programme, were similar to those which have been identified as common to large scale child rearing facilities and detrimental to children's overall health, development and well-being (Spitz, et al 1945; Rutter, 1998, 2007; Nelson et al, 2014). In relation to this research, it, can be unequivocally stated that Goffman's concept of the 'total institution' is played out through every aspect of Institution X, whether structural or organisational, in relation to the treatment of the children within it.

The responses from the participants confirmed much of what the literature presented in chapter two. Their accounts chimed with the literature outlining the historical and political situation in Bulgaria, including the legacy of soviet ideology, in influencing practices of segregating and institutionalising children with impairments in large scale facilities. In addition they highlighted the recent economic instability of Bulgaria and the poverty and instability associated with this as a contributory factor to the huge growth in the numbers of children being admitted to such institutions (Sotiropoulou and Sotiropoulos, 2007; Becirevic and Dowling, 2014).

Their explanations also alluded to dominant negative societal and cultural attitudes towards disability and towards other minority groups in Bulgaria, leading to stigma and shame which has influenced their over-representation in institutions. In Goffman's (1963) terms, the disabled children placed in Institution X in Area A have been

discredited due to their 'visible' stigma (i.e. their impairment). The 'diagnosis' of an impairment at birth within the dominant ideological discourse of personal tragedy and shame, could also be seen as 'medical othering' (McLaughlin and Goodley, 2008), and subsequently contributing to the 'unmaking' of the child (ibid). This is similar to Goffman's idea of the 'mortification of self'.

The social model of disability offers some explanation towards the experiences of the children in terms of attitudinal barriers and the power of medical professionals to determine their lives (Cameron, 2014). Recent research specifically in CEE/CIS countries and in Bulgaria, as flagged up in chapter two, has included the voices of parents who have reported feeling powerless and under pressure from medical professionals to hand their disabled children over to the state, often being told the children's lives will be better than if they were to remain with their families (UNICEF, 2010; Mulheir, 2012; Bilson and Larkin, 2016). The 'better life' discourse is also embedded, as noted earlier, in to Soviet familial ideology whereby the state is seen as an acceptable 'parent' for the child. The practice of placing children in institutions in Bulgaria is therefore woven into recent history and cultural expectations.

Participants' understandings of the reasons for the institutionalisation of children with impairments in Bulgaria echoed the medical model and findings of previous research (Mladenov, 2011; Shakespeare, 2000; Swain and French, 2013), noting embedded historical soviet discourses around family life, childcare and disability (Rassel and Smirnova, 2014). For the children in this study, being born with an impairment, alongside economic transition in Bulgaria following the collapse of the communist regime, heightened other social factors and instability, which could potentially have added to the pressures on families to give their children over to a 'better life'.

From the accounts presented here by the Babas, the professionals, NGO staff and volunteers, a picture emerges of Institution X, specifically Area A, as exhibiting the

features of a 'total institution' as defined by Goffman (1963). As established in chapter two, there is no universally accepted definition of institutions, but writers have instead found it useful to focus on common features of 'institutional culture' (European Commission, 2007, 2009; Mulhuer, 2011). Life in Institution X reflects definitions of institutional culture in that it is designed around a set of rigid routines that meet the needs of the organisation, not the individuals within it. This means that staff, too, are institutionalised. Responses from the Babas and other participants demonstrate that children have been anonymous and invisible both within the institution and within the wider community. Further, having experienced prolonged periods of separation from their families, the children in Area A have also experienced a 'key defining factor' of institutional culture in having been placed there for an indefinite amount of time.

As established in chapter one, most of the children in Area A were placed in Institution X at birth, or during their first year on diagnosis of their impairments. It can be argued, as is suggested in some of the comments made by research participants, that this relates to both the cultural stigma of having a disabled child and the economic burden. However this comes about, all the same, the children remain institutionalised for many years without the appropriate care and attention required for their optimal health, development and well-being. Consequently, the children in Area A have experienced the acquired impairment and further developmental delay common to institutionalised children (United Nations, 2006; Nelson et al, 2014).

In terms of the five 'rough' groupings of institutions provided by Goffman (1961), Institution X would initially seem to fall into the category, 'to care for persons thought to be both incapable and harmless; these are the homes for the blind, the aged, the orphaned, and the indigent' (Goffman, 1961:6). However, from the responses presented here, it appears that in Bulgaria, children born with impairments have traditionally been 'hidden away' from their families and communities due to the stigma

of disability. For the children in this study, all of whom have impairments or medical 'conditions', it can be assumed that Institution X has indeed been used as a 'dumping ground', storing those who are 'marked' or 'blemished' and therefore stigmatised, discredited and dehumanised (Goffman, 1963). Using this interpretation, then, Institution X fits not with the first, but with the second, of Goffman's 'rough' groupings; 'places established to care for persons thought to be at once incapable of looking after themselves and a threat to the community, albeit an unintended one' (Goffman, 1961:16).

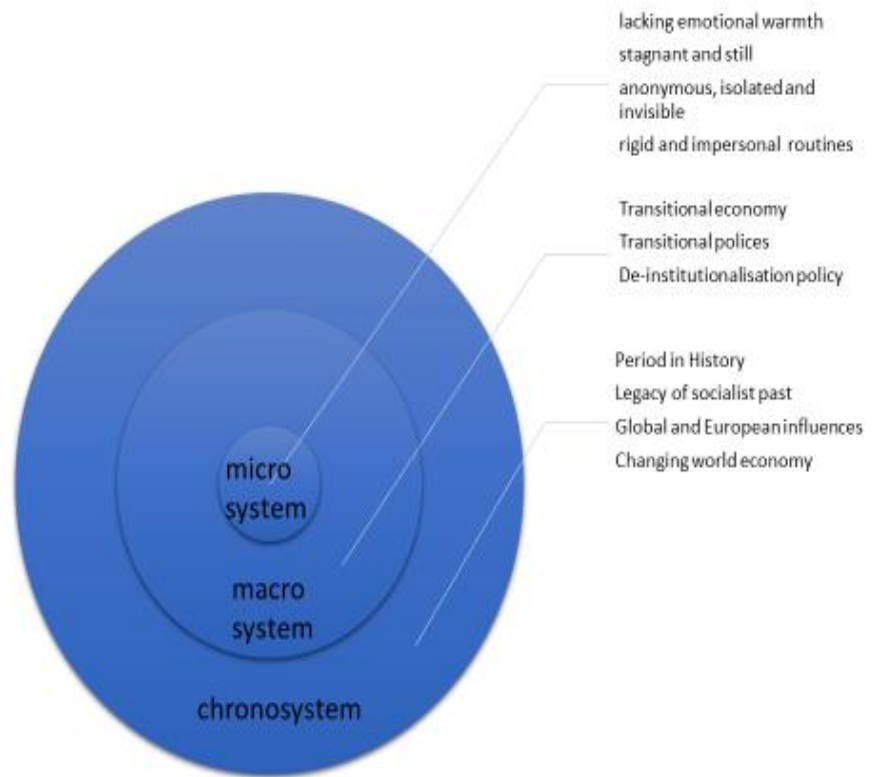
From these accounts it is apparent that Institution X reflects the features of a 'total institution' through having a regimented routine and a strict timetable which meets the needs of the institution, as noted above. In addition, the lack of emotional attachments and positive interactions, stimulation and opportunities for exploration and discovery, whilst not focused on by Goffman, may be inferred from his definition. They have experienced institutional practices that are 'in stark contrast to the needs, and human rights, of the child' (Mulheir, 2011:129) and a totalising regime whereby 'the entire life of the child takes place there' (European Commission, 2009).

Taking into consideration all of the research presented in chapter two documenting the 'developmental hazards' of institutional care (Nelson et al, 2014), reports from participants' about the presentation of the children when they first met them can be read alongside this to assume that the children in Area A have suffered accumulative 'toxic stress' and delayed development (Gunnar, 2001). In fact, it could be suggested that even the children's most basic survival needs were compromised due to inappropriate feeding practices and the lack of a caring and responsive caregiver to notice and respond to their needs in the first place. It can also be established that these children have been caught in the liminal space of the gap between the policy

rhetoric and the policy reality, or the 'liminal space' (Stryker 2012) between the transitional economy and the new policy of de-institutionalisation.

The microsystem as it typically exists for children cross culturally, using Bronfembrenner's perspective (1979, 1986) can be seen as an intimate space of primary relationships which gradually develops to support the child to engage with an increasingly complicated world of complex interconnections. However, in stark contrast, the microsystem of the children in Institution X, as an example of the 'total institution', is one that can be described as 'stagnant'. Placing a child in a cot without an adult (or even another child) to facilitate and mediate the links with other 'micro niches' and wider systems, means that the child rarely has opportunities to act upon their own world. Further, given that they are rarely lifted from the cot, the world has to come to them. The microsystem is therefore characterised by a stillness, or inertia, which involves the child being at the receiving end of a range of 'done to' practices, thus reinforcing perceptions of children as passive, dependent objects. The simplified model from Bronfenbrenner, (1979) (Fig 3 below), so linking with the discussion in chapter two about the significance of child development theory, presents a summary of the ecology of each child in Area A before having a Baba.

Fig 3- the microsystem of children in Area A before having Babas.



Bronfenbrenner proposes that ‘human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in the immediate environment’ (Tudge et al, 2009) Critically for the children in Area A, Bronfenbrenner also proposes that to be effective, the interactions need to take place over a sustained period of time, and on a regular basis.

In Bronfenbrenner terms the ‘proximal processes’ which are key to the child’s early development, and usually happening within the context of close relationships (ie. the term ‘proximal’) are actually more ‘distal’ in that there is a detachment from the child psychologically and physically in the institutional context. The missing ingredient appears to be the ‘interactions’ between people, objects and the environment for the

children in institution X. In relation to the key three child development themes presented on page 35 in chapter two; the children do not have responsive caregivers, their environments are disabling and in terms of their cultural environment, the orphanage appears to represent a 'cultural artefact'.

In conclusion, and drawing together both developmental and organisational theory, the work of Goffman (1961; 1963) and Bronfenbrenner (1979; 1986) became critical in assessing the role of the Babas. In part this is because the quality of the proximal process over time emerges as the most powerful indicator of developmental outcome and it also has the effect of reducing or buffering against harmful environmental differences. Further, establishing what life was like in Institution X was important in order to go on to analyse the caregiving role of the Baba and their role in supporting the de-institutionalisation of the children in Area A. Consequently, the next chapter focuses closely on the micro ecology of the child, the immediate space of the child's world, and so the potential impact of the Baba.

Chapter Five

Everything a normal grandmother would do

5.1 Introduction

In chapters two and four, I established the context for institutional care in Bulgaria. In chapter four I also presented findings to demonstrate that Institution X exhibits the features of a 'total institution', and as such, has provided an environment which is at odds with the expectations of conditions to promote the overall health, well-being and development of the children (Bronfenbrenner, 1979; Dozier et al, 2012; Myers, 1992; Mulheir, 2012; WHO, 2012). In chapters five and six, I present findings and discussion about the caregiving practices of the Baba, talking through how they can be seen as providing an alternative model of care with the potential for offering a protective layer to the children, buffering the multiple and harmful risk factors of the 'total institution' regarding children's development.

This study is qualitative in nature and I did not set out to 'measure' the children's developmental gains in a positivist manner. However, as developmental harm is a significant and life limiting outcome of institutional life for children and is presented as a human rights rationale central to progressing the de-institutionalisation of children strategies (WHO, 2012; Conroy 2014) it did form a central part of all the interviews with participants. In my conversations with the Babas I asked questions about 'their' children, for example, 'tell me about 'child B' when you first met them?', 'what could 'child B' do when you first met them?' and 'what can 'child B' do now?' With all the other participants I asked, 'could you give me an example of a child who has benefitted from having a Baba?'. From their responses, it is evident that all of the children mentioned in this study benefitted from, and made developmental progress whilst having, a Baba; although to varying degrees, with some making far more progress than others.

To further contextualise these findings and discussion, in her interview, Susan, an NGO representative, explained how decisions were made about which children

should be allocated a Baba at the beginning of the programme. She commented that the initial thinking was that these allocations would actually be palliative care, which makes the children's improvement very notable. Her comments also highlighted the general improvements she witnessed in the very early stages of the programme.

Susan said:

It was so difficult to make the decision because all of the children in the institution are desperate for one to one attention, however, we made a decision that the children who appeared to be the most in need would get a Baba, and we thought it was going to be palliative care... I was surprised though because once they had a Baba, even the children who appeared to be extremely malnourished, fragile and the most disabled, started to grow and develop within weeks.

Susan NGO

Most of the children had entered the institution at birth as a result of being born with impairments, as stated. These were wide-ranging and included Down's Syndrome, Cerebral Palsy, Restricted Growth and Disorder of Sex Development or Ambiguous Genitalia. However, I present a timely reminder here that some of the children in this study may have entered Institution X without impairments, or with minor impairments that would not impact on their cognitive, physical and emotional development. Some of these children, at the time of the research interviews, were entering their teenage years without having met any of the typical developmental expectations of a young child, for example being unable to sit up, feed independently and communicate effectively. Regardless of the potential developmental delay in specific areas that might be associated with the child's impairment or medical diagnosis, these children were all demonstrating extreme developmental harm, which means it can be assumed that they had been exposed to the inadequate conditions and 'developmental hazards' referred to by Nelson et al (2014), of daily life in a 'total institution' over a long period of time.

It is also important to mention at this point that this research and the surrounding literature suggests that an over-reliance on the model of defectology sometimes leads to misdiagnosis (Mladenov, 2011). The model can mean that a label is applied and the child is viewed according solely to that label (Rosenhan, 1973), irrespective of accuracy. Nelson et al (2014) reported that many of the caregivers in his study understood the children's significant delayed development solely as a result of their original reason for being admitted in the first place (ie their medical diagnosis, or impairment label) rather than as a result of years of institutional care.

I experienced an example of this potential mis diagnosis when I was told by members of staff that one of the young children I was working with as a volunteer, who was only two years old, was in the institution due to schizophrenia. It became apparent that the child had, remarkably, been labelled with this diagnosis at birth because her mother had a diagnosis of schizophrenia. Similarly, when I queried the very low weight and small size of two very small children with Down's Syndrome I was told, with great authority, that these children had a type of Down's Syndrome which meant that they also had a growth hormone deficiency. Subsequently, these children were both adopted overseas. After hospitalisation in their new countries they both rapidly gained weight and substantial growth continued in their adoptive families.

These concerns and narratives about misdiagnosis were not limited to volunteers. Susan, of the NGO, for instance, spoke about the case of a child who she saw standing up in a cot smiling and waving at her. She stated that, in contradiction of this evidence, the plan of care around the child was founded upon his diagnosis as 'paraplegic'. Even when she pointed out that the child was obviously moving his lower limbs and could therefore benefit from being out of his cot, they insisted that he was paralysed from the waist down.

Issues like misdiagnosis were countered, to an extent, by the introduction of the Babas programme, given their increasing familiarity with the children and ability to fight on their behalf. Further, as noted, the introduction of the programme led to swift changes in the children. However, as I have already established, it was not the extent of the children's developmental progress that I set out to understand, but the nature of the daily interactions and encounters between the Babas and children and how these could potentially contribute towards de-institutionalisation. Consequently, having set the scene, the following sections show *what the Babas do* with the children i.e. their daily routines, encounters, interactions and ways of relating to the children, and to consider *how* these encounters instigate and support developmental changes and why they are meaningful in terms of the study focus.

The framework for analysis is developed primarily from theory and research on caregiving practices and Early Child Development (ECD) theory which is typically used in relation to the holistic development of young children up to the age of 8 years. In doing so, as outlined in previous chapters, I am remaining cognisant of the view of Mevawalla (2013:290) that 'ECD is a local, related and multi-faceted affair'. In this way I am drawing from child development theories and perspectives but applying them in a manner which takes account of the local context. The use of ECD theory is not intended to 'infantilise' some of the older children, rather, it is used with the understanding that these children entered the institution at birth and have therefore missed out on the fundamental environmental and emotional conditions needed by human infants (with or without impairments) around the world, to support and enable them to reach their optimal developmental potential (Empson, 2015).

In presenting the themes generated from my data analysis (outlined in table 4 in chapter three), which provide an insight into the role of the Baba, I was uncomfortable

with the idea of separating the caregiving activities and related areas of development as to do so seemed at odds with the holistic approach underpinning the study. Likewise, due to the complex and interwoven nature of children's development, it took time to decide on the order in which to present each aspect of caregiving, as I did not wish to imply they were in order of significance and importance. I eventually decided to present the findings and discussion in the following order; firstly, in chapter five I explore the interactions that promote children's survival and growth, including protection, food and healthcare; secondly, in chapter six, I show the interactions necessary to promote the development of identity and a sense of self, the development of trusting relationships and attachments, and to support and encourage stimulation and exploration. Bornstein and Putnick's (2012) categorisations of 'caregiving' were helpful in my decisions, as the themes align quite naturally with the categories of nurturant caregiving, material caregiving and social caregiving outlined in chapter two as typical caregiver/parenting practices within family contexts.

Notwithstanding the enhanced needs of children with impairments and medical/health conditions, as noted earlier in the study, the premise of this study is that *all children* have a 'need for', and a 'right to' caregiving practices and experiences which promote their opportunity for their survival, well-being and optimal development. It should also be noted that throughout these chapters, unless the participants have specifically referred to the child's health condition or impairment, this will not be addressed unless it is required to support the analysis.

I was informed by research participants Kalina, Susan and Todor, who were involved in the development of the Baba programme in Institute X, that carrying out routine intimate caregiving tasks with the children was not initially intended to be part of the Baba's role. It was assumed that the staff of Room A would provide this type of care as part of their typical daily routines with the children. The primary intention of the

Baba role was to give the child a 'significant other' with a focus on attachment. However, from analysis of the interview data it became clear that when the Babas first became involved with the children, their immediate physical survival and protection needs took precedent over every other aspect of caregiving. This is understandable when considered alongside Susan's comment about Room A at the beginning of the Baba programme that 'the scale of the lack of hygiene and the malnutrition was just breath taking'. Additionally, when asked about their role, all the Babas mentioned feeding, bathing and dressing the child before anything else. My intention as a reflexive researcher was always to give priority to the voice of the Babas so this became the starting point to present the findings and discussion of the Babas' role.

5.2 Feeding the children

During analysis of the transcripts, I became aware that the Babas appeared 'pre-occupied' with feeding, as they all immediately provided answers relating to feeding when asked about 'their' children. They commented on progression from liquid to solid food, and whether the child could now feed themselves with, or be fed from, a spoon rather than receiving their food from a bottle held by a caregiver or propped up in the cot. They also commented on initial feeding difficulties and whether these had been resolved. Typical responses were very descriptive, as illustrated by Baba Rositsa and Baba Petya:

He's very good eating with the spoon, also he can eat solid food.
And now he is used to looking for the puree once he finishes his
afternoon snack.

Baba Rositsa

When I began to take care of him he was on a bottle with a teat, but
now he can eat with the spoon, he is eating well.

Baba Petya

Other Babas commented on feeding as the most pleasurable activity for the child:

I think the food is his biggest pleasure. He is always hungry. He just needs to see me and immediately open his mouth.

Baba
Margarita

Susan provided some further context which helped to understand why feeding appeared to be a priority in discussion. She explained that in the early days:

we knew that we weren't going to get the institution to change the feeding, so we had to address that, so we said that we would provide a puree to the children but the purees had to be fed by the Babas, and we also said to the director that we wanted the children to put on weight and we made a big song and dance about weighing them every time.

Susan NGO

It appears, then, that improving feeding practices had been at the forefront of expectation regarding the Babas, and as this had already been monitored on a regular basis, it had become an aspect of their work they felt comfortable with and were well-practiced at discussing. Upon further consideration, it occurred to me that when asked to recall their initial impressions of the institution, most participants commented on the malnourished appearance of the children and the inappropriate feeding practices. I recalled my own shock as a volunteer at the way children were fed, and my own determination when feeding the children that they needed to finish every last drop. All of the volunteer participants similarly recalled poor feeding practices when reflecting on their own first impressions of Institution X. Rebecca, for instance, shared her observations of typical feeding practices in Room A:

they would have glass bottles full of pretty much, some had milk-water or some had gruel - this liquidly old thing, put into old alcohol bottles or beer bottles, and put one of those dummy ends onto them... Yes, a teat. Sometimes they'd cut bigger holes in them so the food could go down a lot faster, quicker. But they would usually prop the glass bottle up on a pillow, so force-fed themselves, which meant they didn't necessarily eat it. Some had swallow reflexes, some would be sick, they would choke a little bit, or whatever but it was rare that you ever saw the carers in the orphanage feeding them properly.

Rebecca, Vol

I reflected that the Babas' focus may indeed be related to a habitual and expected response linked to previous monitoring of their role by the psychologists and NGO rep. However, drawing from my own experiences as a mother, grandmother and volunteer I reconfigured this 'pre-occupation' with feeding as an indication that they perceived themselves as the child's primary caregiver. I also recalled my own anxieties as a mother when my babies had periods of not eating well, and more recently, as grandmother of a child that I often worry about due to their having a range of dietary intolerances. This was reinforced by Kalina, who likened the role of the Babas to 'everything that a normal Baba or mother would do'. Like me, she seemed to be drawing from her own experience as a mother when she said:

feeding is trust and is part of building the relationship with Baba and child, like when you have a baby the first thing you do is feed the baby and its very important.

Kalina, NGO

For the primary caregiver, feeding is about their child's survival before anything else. As noted by Bornstein and Britto (2012:19) 'survival is ensured through provision of nourishment and protection', and like most parents, the Babas were therefore anxious about their child's nourishment, survival and subsequent weight gain. Weight gain was reported by the Babas and some of the other participants in the study which appears to be a result of the improved feeding routines and practices introduced by the Babas, however, this could also be explained as a result of feeling loved and experiencing sensitive human contact. This is addressed further in chapter five.

The skills and experiences of the caregiver are significant in the type of care children receive (WHO, 2004). In contrast to the early interactions of new babies and new parents who have time to get to know each other and work out how to relate to each other, the Baba/child relationship is developing from a position of many years of extreme isolation, lack of appropriate nurturing and subsequent developmental harm

for the children. The WHO Review of Caregiving (2004) highlights the challenges faced by caregivers in adjusting to the feeding requirements of a poorly child or a child with impairments, stating that 'it takes a caring and skilled caregiver to encourage a child to eat and drink under these circumstances' (WHO, 2004:2).

Using Stern's concept of 'the dance' (1997) in understanding early interaction patterns between the baby and carer, it could be assumed from the evidence in chapter four that prior to having a Baba there have been only 'mis-steps' in the dance. With the introduction of the Baba, both parties have to learn how to read each other's signals. For the child who has been institutionalised since birth, and who has therefore learnt their cues to gain attention remain unheard and unseen, this can be a long and potentially confusing journey. The child is therefore, in the early days of the relationship, reliant on the Baba's own skills in interpreting and responding appropriately to their needs. The interview extract below, for instance, demonstrates Baba Margarita's experience, skilled observation and tacit knowledge of children's development (Myers, 1992). Baba Margarita discusses Denis's (aged 2 years) development from a sucking schema to eating from the spoon, linking this with his physical development:

BL: He was with a bottle, again like Dida, I don't know whether the Baba before me was trying to feed him with a spoon. When he had the spoon in his mouth he was sucking, he thinks this is a teat. But if you see him now you wouldn't believe it. He is eating with the spoon. The consistency of the food is very thick now. Inside the Room A I don't know how they feed them. The feeding isn't a problem for me now, he can open his mouth very well, it's even a pleasure for me.

L: Why do you feel that's important that he is achieving these milestones?

BL: I think that the food is the very basic thing. Just imagine, with a bottle and teat, what kind of liquid he is eating?! But now I feel he even started having muscles, yes.

The act of feeding the child, for their survival needs, has other significant elements worthy of consideration here in relation to the de-institutionalisation of the child. In the continuation of my interview with Baba Margarita, for instance, she demonstrates her understanding of how her role in feeding can influence other aspects of the child's life. She explains that:

I think food is his biggest pleasure. He is always hungry. He just needs to see me and he immediately opens his mouth. For this reason I had to be very communicative with the staff and now already I can get on well with the health care assistants and they are giving him a thicker food consistency', she adds, 'Once he is full he is very calm.'

Baba Margarita

The pleasurable aspect of the food and the calming effect it has links to the arousal cycle central to psychoanalytical attachment theories (Winnicott, 1964) and the beginning of attachment. The opening of his mouth as his Baba appears suggests that the child associates the Baba with the pleasurable activity of feeding, which is core to building up his trust in her. It also suggests the development of cognitive processes such as association and memory (Bornstein and Lamb, 2011, Santrock, 2015). Winnicott (1964:30), stated that 'infant feeding is a putting into practice of a love relationship between two human beings', which would appear to reflect the concerns Babas expressed about their children's feeding habits, and the amount of effort they put in to the feeding routines. In addition, some participants told me about Babas bringing food in from home, in the form of special treats or 'extras' used to convey love and affection for the child.

Baba Margarita's account of her communications with staff (above) suggests that she is positively influencing staff caregiving practices in the institution, and has an expectation that the child's specific food needs will be met by staff in her absence. This signifies an element of 'de-institutionalisation' stemming from a change to the practice of 'feeding'. The Baba, herself attuned and responsive to the child's individual

needs is sharing this information with the staff, and in doing so she is giving the message that this child is no longer anonymous, and has someone looking out for him.

During the interviews, one of the final questions encouraged responses from Babas about concerns for their child's future. Some Babas expressed concerns about their capacity for survival and self-care when and if their child is transferred from 'Institution X' to another institution. Supporting these children in their transition from liquid feeding from a bottle to independent feeding of solid foods using a spoon could serve as a protective factor for them whether they remain in institution X or move to other, potentially adult, large institutions or small group homes. This was summed up by Susan:

we started in October and I went back in March and the thing that struck me most is how talkative and how proud the grannies were, you know they loved talking about what they were doing and we noticed a couple of the children had learned how to eat with a spoon, and you know, we had told them to focus on feeding as being a nice time, nice thing to do not least because we thought that if they learnt to feed well with their granny then they might be able to feed better with the staff and might be able to hold the bottles themselves, just because, don't forget they were still on liquid diets back then...

Susan, NGO

Ana also highlighted the protective nature of the children's increasing independence in terms of being able to feed themselves with a spoon stating that:

some of the children will develop self-care which will be important for their lives in another Institution... and that, unfortunately, that is the umm future for some of them.

Ana, Psychologist

These accounts of feeding relate to Daws' (2007) work on the way mothers manage the emotional intimacy of feeding and weaning their babies. She suggests that the actual physical distance between the carer and the baby, how the mother holds the baby or not, can signify the emotional distance between the two. In Rebecca's account

of organisational feeding practices before the Baba programme, noted earlier, she described a child being left to feed alone with a propped up bottle. This illustrates the emotional distance typical of institutional care whereupon staff themselves become institutionalised and have little time to devote to individual feeding routines. It might also signify a deliberate detachment made in order to cope with the challenging emotional nature of the work. At a more critical level, feeding practices in institutional care for children have been reported as another form of abuse and degradation and another means by which they are dehumanised in the 'total institution' (Penglase, 2005). In contrast, Rebecca's account of one of the Babas feeding their child in his pushchair reflects a feeding routine which has positive emotional and social aspects and so is more typical of an everyday child/primary caregiver interaction.

She'd be sat next to him, and feed him, and play with him, just like a toddler at home really.

Rebecca, Vol

5.3 Bathing and dressing the children

As well as feeding, the Babas took on a key role in other intimate care needs of their children. As previously highlighted, this was not an initially intended to be part of the Baba's role, but it evolved once they were in place and it became clear how important this was before the Babas could do anything 'extra' with the children.

It was frequently mentioned by the research participants that they had seen a general improvement in the physical appearance of the children specifically relating to cleanliness and overall appearance. For example, Susan noted this when commenting on one of her first 'follow up' visits during the early stages of the programme:

On the whole you know a generalisation, but for the most part they (the children) seemed a lot brighter, and most of the children had terrible sores and we noticed they were clearing up, they would have

all these fungal infections on their hands and they took quite a while to clear up but you know they just looked a whole lot healthier, and it was very harsh winter when I went up, and we had about 6ft of snow that day, and still the children looked brighter than they had the summer before... they were more tactile and sitting up and more alert and you could just tell from the way the grannies were talking about the children that they knew them and they cared, and although there were no amazing transformations they were just better and it was more progress, you know a little bit of progress.

Susan, NGO

My diary entry number 1, presented in the introduction, recounts my reaction to the smell in Room A and the distressing state of the children who were lying in their own urine and vomit. Susan's comments about the reaction of the first group of Babas reinforces this account, as do some of the others offered in chapter four. It is therefore not surprising that the Babas took it upon themselves to incorporate bath time into their daily routines despite this not being an expectation of their role.

All of the Babas mentioned the cleanliness and 'presentation' of the children when asked about their typical daily routines. This appeared to be for a number of inter-related reasons. Firstly, the children needed to be cleaned because the conditions they were in meant that it was difficult for people to work closely with them due to the smell and infections around their mouths and on their skin, although neither the Babas nor the volunteers mentioned this as a reason for bathing the children. Ana, for instance, noted the importance of the child looking different and being presented to others differently:

It is important because the child looks different so that produces a different uumm response from the adults, because you know, its human nature to not want to communicate with someone who smells for example.

Ana, psychologist

Secondly, when asked 'what does your child like best?' most of the Babas mentioned bathing and provided descriptions of how their child behaved in the bath, thus recognising 'bath time' as a great source of pleasure for the children. Baba Rositsa's

description of her children at bath time also indicates her understanding of her children's individual differences and needs:

Desislav is very excited when taking the bath, he is screaming, moving his hands, his legs, he is so happy, he is laughing. He only needs to see the tooth brush and he immediately opens his mouth. He likes the bathing very much. You can see him having real fun and joy, the opposite of Tsvetan.

Baba Rositsa

A third reason was, as with feeding, some of the Babas noted bath time as a means of encouraging the children in their development of independence and self-care. Baba Ekatrina told me that a lot of her time was spent '*teaching*' Michele to '*keep herself clean*', which also reflects her desire to encourage Michele's sense of self and understanding of her own individual needs. She explained her typical routine with Michele, stating:

Well the first thing I do when I get there is to help her to take a bath, and she likes it, and then to change her clothes from her old clothes (here she means the 'institution clothing') with the new clothes (clothes she has brought from home).

Baba Ekatrina

Here, the term '*help her*' implies that the Baba is expecting and allowing Michele to lead the action, demonstrating how bath time acted as a means to support Michele in developing her independence and self-care skills. For Michele, feeling clean was additionally noted by Todor (Psy), and Susan (NGO) as a critical aspect of her developing sense of self in relation to her own personal history. She was placed in the institution at birth due to a condition linked to ambiguous genitalia and over many years had undergone a series of operations to become female. As a result of these surgeries she wears a colostomy bag. In describing her first meeting with Michele, Susan noted:

She was 5 and she was hugely malnourished, she looked like she had acute malnutrition she had the swollen belly, and a colostomy

bag and her legs were effectively withered, and when I walked in I saw a really miserable, very pretty little girl who, umm she was intersex so everyone sort of said, you know, 'is she a girl or a boy?' ... she could only roll onto her tummy which was uncomfortable with the colostomy, and I never thought she would walk and at that point I just thought she's a beautiful little girl who was very bright and all she could do was smile... the granny said she had to give her lots of confidence about the colostomy because she smells herself a lot and she gets really upset about it so she said 'I've done a lot of telling her, you know, you're fine, you're clean, don't worry.'

Susan, NGO

Susan's account demonstrates that Michele's Baba is attuned and empathetic, being sensitive to Michele, understanding her confusion and supporting her developing self-awareness. In being able to read and understanding Michele's feelings she is also demonstrating mind mindedness (Taylor, 2012).

Another reason was also clear, as when telling me about the importance of their children being clean and presentable, comments from the Babas, and at times their facial expressions, implied that their clean and well-presented children were a reflection of themselves as the primary caregiver. They spoke confidently and assertively about their role here suggesting a sense of pride in doing a good job. All the Babas had rejected orphanage clothing in favour of freshly laundered clothes that they brought in from home. Baba Margarita notes that:

It's important for them to be clean, tidy... I have some of their clothes that I am careful about. When the children are with me I don't use clothes from the Section. I have some clothes that I have chosen before and in it the children look nice. I take these clothes home with me, I wash them and then I use them again.

Baba Elisaveta adds to this with her explanation indicating the stigma or 'blemish' associated with coming from an 'orphanage'. This is interesting because whilst her children have visibly noticeable impairments she doesn't appear to be referring to 'disability' as stigmatised. It appears that the stigma of being an 'orphan' in a sense trumps this. In writing about 'stigma', Cameron (2014) refers to 'passing' as the process used by some disabled people to hide their impairment in order to 'pass' as

non-disabled. In this sense the Baba is 'passing' the child as a 'non orphan' thus reducing the stigma that she perceives as being attached to the orphan identity. It is also significant that the term 'normal' in her comments is not being used to imply 'non-disabled', rather, she implies the normality of being 'cared for' and 'cared about' in a familial context:

The hygiene is very important, and also I like them to be clean, this make me feel good also. When other people see them, I am happy they look good. I don't want them to think that because the child is from an orphanage it's a reason to not smell good. I simply want them to be normal children that someone is taking care of.

Baba Elisaveta

This theme is addressed further in chapter six in relation to identity. Finally, bath time presented an opportunity for trusting relationships and attachments to develop between the Babas and their children. As Susan commented, there were positive changes after new baths were introduced to the institution as part of refurbishments:

...so we said to the grannies to bath the children before you have them, and we found in a roundabout way, that it actually helped to encourage the bond, and even in the most disabled children they would say, you know, 'he loved the bath, and ooh, they love the water', and also it made it obvious that the children had never been bathed like this before, and I think it stirred additional emotion in the grannies and sort of helped.

Susan, NGO

5.4 General Health Care

The general health care needs of the children were identified as another key aspect of the Babas' role and one which illustrated further the protective aspect. Like Baba Margarita making a request for a different consistency of food for her child, Babas were observed making demands from the staff in relation to their child's general health and well-being. One volunteer described an angry encounter she had observed between a Baba and a member of staff, whereupon the Baba insisted on staying with her child at the end of their session until the staff member brought medication for him.

Without the Baba's insistence the child would have remained in pain. Bev recounted the story, one which was also mentioned by two other participants:

One of the Babas brought her child back to Room A. She put him in his cot and went to get a nurse and brought her back to his cot. Her voice was raised, she was speaking in a really angry way, really angry, to the nurse who was shaking her head and arguing back. I couldn't understand what they were saying but I could see that the Baba kept pointing at the child and touching his forehead as if to say, 'look, he's got a temperature, he's not well'. So, they argued for ages then the Baba went off to get the psychologist. When the psychologist spoke to the nurse you could tell she was still angry but she went and got the child some medication. The granny then stayed with the child until he was properly settled, like, and that the medicine, had worked, I think it was like Calpol. I remember it so well cos all the volunteers were laughing about it afterwards, cos the granny got so angry she was quite scary.

Bev, Vol

Another volunteer recalled similar incidents demonstrating the protective role of the Baba:

There was a little boy who had Down Syndrome...and he had a cold once, and she'd bring stuff in for him and put Sudocrem cream on his nose. And I know the nurses did that as well, but, I remember, once she came into Room A and she saw his face, because they, (nurses) had just smeared it all over his face, and she said 'uugh' and wiped it off and tidied up his face with such care and stuff. You could really tell the relationship between them.

Jane, Vol

Jane also reminded me of an incident when volunteers had taken children out of the institution into the grounds for fresh air and play:

We took the children onto the swings which were in the shade, but I remember the Babas coming and saying "that's my child, it's too hot for them to be out here."

Jane, Vol

This incident reinforces the impression that the Babas had established themselves as the primary carer for their children, although they were working alongside staff in the institution and at times with volunteers.

As noted in Myers, (1992:44), 'all children have basic needs but each child will have their own set of individual needs'. For the children in this study, the consequences of

spending their whole lives within the total institution, means that they are in fragile states of health and vulnerable to further harm. For Baba Rositza, it was especially important for her to consider the additional needs of Desislav, a child with hydrocephalus, showing how her capacity to review and adapt her own caregiving practice developed, and how she used limited resources creatively in order to best support and meet his basic needs. This was evident in her description of when she first met Desislav:

Desislav was only lying down, he even couldn't be half sitting, I was supporting him with a small blanket in order to give him the food. His food was also in a bottle. But he could not stay longer than half an hour with this blanket supporting his back in the baby pram. Then I had to change the first pram with another that would allow him lying horizontally. He was just one little tiny body, and a big head.

Baba Rositza

Likewise, Baba Elisaveta explained her attempts to understand and respond to the individual physical needs of Nikolai, a little boy who was born with lower limb reduction, so his legs are not fully formed. I first met Nikolai on my visit to the institution in 2010. At the time it bothered me that although he appeared to be a friendly little boy who engaged well with visitors and attempted actions to invite contact with others, for example putting his hands up to be held, the staff would not allow him to be lifted from his cot and taken to the playroom as they felt that his 'condition' made him too fragile. Whilst the staff in this instance appeared to be acting out of a genuine concern for him, I was concerned using this rationale, he would be trapped in his cot forever. In contrast to this lack of movement and contact Baba Elisaveta told me how she supports his developing physical exploration, at the same time being aware of his impairment related needs:

When we go out I try to give him more space, even we go out more often for him to be able to crawl. I am doing this because when he is sitting in the pram his tummy is under pressure and he has poo

very often. The time I spend with him usually 3 to 4 diapers need to be changed.

Baba Elisaveta

Baba Elisaveta goes on to say more about Nikolai's activities, something which also implies her desire for him to develop his strength in his upper body, suggesting that she is challenging limiting assumptions of his potential abilities.

He is a very strong boy, he is hanging on his hands, such a little creature and so strong...he can stand on his head. This is important because he needs to compensate for other things.

Baba Elisaveta

The Baba is therefore challenging the staff's perceptions of Nikolai as a passive and vulnerable victim of his disability. In doing so, like Baba Margarita's insistence regarding staff feeding Denis, she is also contributing towards his developing sense of agency, control and resilience.

Finally, there are professionals contributing to the increased development of the children alongside the Babas as part of the programme, although the Babas are key, hence the use of their title in the name. The importance of the Babas as the co-ordinators of the different aspects of 'therapy' in the institution that the children were given was evident. This particular programme employs physiotherapists to include regular massages as part of each child's routine with the Babas, and regular meetings with the two psychologists attached to the programme. The impact of the Babas on how the children responded to professionals was significant. For example, Boyan noted the change in the children now attending sessions with their Babas rather than being brought by a carer from the institution explaining that:

In the beginning, most of the children didn't like to be touched or undressed, and it was very important for the baba to be there, so they can feel there presence, and their voices just to be reassured that its okay for them to be having this type of contact.

Boyan, Physio

5.5 Summary and discussion of chapter five

All these physical and intimate care needs are met by the Babas in ways which reflect sensitive and responsive caregiving practices attuned to the children's individual needs and contingent to their different situations. The Babas are demonstrating their capacity to tune in to and interpret the children's signals to react in ways that are most suited to the children's needs, thus enabling more positive health and developmental outcomes for children (WHO, 2004). Like foster parents in Schoffield and Beek's (2005) study, the intensity of the degree of 'pre occupation' (Winnicott, 1964) Babas had around these basic needs was typical of new parents of infants and reflected their understanding of their child's needs. Their accounts, especially around feeding, often mentioned some difficulties in the early stages while they were getting to know their children, but also reported overcoming issues with time, patience, understanding and effort. This trial and error pattern is typical of most parent/infant dyads, and plays a role in the child's developing resilience as they learn to adapt their own techniques within the relationship (Music, 2017). Even when the parent gets it wrong sometimes, the child is able to learn that with time, and further attempts, their cues are responded to. In attending to the child's immediate survival and physical needs in this way the Babas have demonstrated 'maternal commitment' which is identified in caregiving literature as the best prediction of 'infant survival' (Music, 2011: 52).

What the Babas said led me to consider their importance as experienced caregivers coming to the caregiving relationship with a source of tacit knowledge, or 'traditional wisdom' (Myers, 1992; Bornstein and Lamb, 2011). Certain aspects of these accounts stood out to me in relation to this, particularly around adapting their caregiving practices to meet the specific needs of their children. To do this effectively involves the Babas in a three-stage process which is lacking in institutional facilities

such as Institution X. The Babas are 'noticing' what is going on for the child. However, in order to do this they are first 'recognising' the child as a human worthy of 'noticing'.

Finally, they 'respond' by acting. I start here by stripping back the terminology of attachment theorists and reverting to basic Oxford Dictionary definitions. I acknowledge the 'simplistic' nature of using such definitions, I use them in a deliberate attempt to identify key features of the Babas' caregiving practices in order to analyse how they counter the ideology of the total institution.

Firstly, *To Recognise*, or, to '*acknowledge the existence of*' is particularly important given that a key characteristic of a total institution is the dehumanisation of the 'inmates'. When a child is dehumanised they can more easily be objectified and this is when harmful and abusive practices are more likely to become part of the institutional regime. Secondly, *To Notice*, or, '*the act of observing or paying attention to something*' is critical in the relationship because in order to respond sensitively and appropriately, the Baba is able to understand what is happening for the child. For example, this is evident when Baba Margarita '*noticed*' the reason why Denis couldn't eat from the spoon, and in Bev's account of the Baba '*noticing*' that their child had a temperature, and even Baba Rositsa '*noticing*' that Desislav's head needed additional support. This 'noticing' was prominent in most of the Babas' comments and descriptions of their interactions with the children. I also recalled the impact of the lack of 'noticing' in some interactions, for instance, on the part of the Director of Institution X when she proudly pointed out the matching bedding on the cots (my diary entry in chapter one), so emphasising structure and organisation, echoing ideas of the total institution, rather than individuals and their 'conditions'.

Finally, *To Respond*, or, '*to do something as a reaction to someone or something*' is also apparent when noting the sensitive and attuned responses from the Babas when attending to the survival and protection needs of the children. Such responses are critical for these children who have experienced severe trauma and harm in their experiences of caregiving in their earlier lives.

For these children, recognising, noticing and responding as they are described here have not been a consistent part of their developmental history prior to having a Baba, reflecting their institutionalisation. In typical families around the world, parents and caregivers, even those under extreme pressures, the 'noticing' of the child comes from foundations of relationships that have been built up over thousands of basic interactions during the first days of life and beyond. The act of noticing comes from knowing the child, which comes from time and effort in the relationship. For the children in Room A these foundations have not been established which reaffirms the importance of the caregiving experience and knowledge that the Babas are bringing to the relationship and shows what they may be contributing regarding de-institutionalisation. These three features are core to attachment concepts such as attunement, responsiveness and sensitivity.

De-institutionalisation may be seen as having caregiving as a central feature. As noted by attachment theorists (Bowlby, 1969; Ainsworth, 1978), by providing for the basic and intimate needs as presented in this chapter, the Babas are helping the children to trust that their needs will be met, in a caring, warm and responsive manner. It is through a child's earliest experiences of caregiving, including the sensitive and appropriate handling and touching of the child's body during feeding, bathing, dressing and activities such as soothing, patting and comforting that the child begins to learn that they are a 'person' and that they exist as a separate entity to others

(Alvarez, 1992). These actions upon the body of the child are critical in helping the child to understand that they exist, that they are 'a someone', and develop an understanding that they are a person in relation to other people, rather than, in this case, an element of an institution. The nurturing caregiving practices aimed at survival and protection of the children, responsive to each child's needs, represent the building blocks for these children and are at the crux of the development of their identity and developing understanding of themselves as individual people with connectedness to others. Physical touch for babies aids their sensory development and the development of proprioception. Touch is also known to stimulate growth (Music, 2011).

Borrowing from Winnicott (1964), the minutiae of these daily intimate encounters between the Babas and children were found to support moments of 'total happenings' where the baba is simply dedicating herself to the child's needs alone for small shared moments. Winnicott describes the 'total happening' as a fulfilling encounter with a patient caregiver consisting of a beginning, a middle and an end (ibid). For most of these children this is the first time they have experienced such encounters. In doing so they begin to experience the world differently. In contrast to the children's daily experiences before having a Baba these features form the foundations of an alternative model of care provided within the institution, one which introduces some positive changes to the child's microsystem. What is also clearly understood, from the Babas accounts, is that in addition to meeting these needs, there are emotional needs being addressed. For example, Baba Rositza demonstrates her knowledge of the emotional needs of children, when she states that:

It's not enough for them to only have bathing, to be eating, but what is more important is the emotional contact.

Baba Rositza

Consequently, the next chapter explores the role of the Baba in supporting the child's emotional needs, including their developing sense of self and identity, in the context of loving and secure relationships. These final chapters are deeply interrelated, something which can be seen as epitomised in the response from Sonya, the physiotherapist, when asked which aspects of the Babas' role were most important. She did not pick out individual aspects, so reflecting the holistic nature of her approach, and that of this study, but instead said,

All the activities are important. If there is no bathing, feeding and clothes changing, there won't be such a good bond between them.

Sonya, Physio

Chapter Six

Somebody's Child

6.1 Introduction

In the previous chapter the role of the Baba was presented in relation to caring for the child's physical and intimate care and survival needs. In caregiving terms, chapter five has highlighted the health, nutrition and responsive care domains of nurturing care (The Lancet, 2016) whereas this chapter will focus more on the domains of safety and security, and early learning (ibid). This chapter presents findings that demonstrate the Babas' emphasis on the emotional needs of the children. In doing so it builds on the work of child development theorists who propose that babies and children need much more than food and other basic needs to develop and thrive (Spitz, 1945; Bowlby 1969, Ainsworth, 1978). The high mortality rates in institutional care, where emotional needs are not met, are indicative of their significance. Indeed, given these mortality rates the Babas programme was developed to address emotional needs. Consequently, when the programme was introduced it was not anticipated that the Babas would also address the children's physical and survival needs⁸.

Here too, the focus is on the potential of the programme for the de-institutionalisation of the children, even within the institution. As a result, this chapter discusses the findings in relation to the child's developing identity as an aspect of the Babas' caregiving practices. Their growing individuality and sense of self locates them as people with rights, an approach to children and 'childhood' that is absent from the institution. The chapter begins with a consideration of attachments and love which support the child's sense of belonging to a Baba and to a wider community, not the institution. The chapter also considers how this has potential to change the identity label which has been attached to the child by others, one which brings with it negative assumptions about the child, suggesting that the negative identity label can become a more positive one.

⁸ The balance in the programme between physical and emotional needs is reflected in the comparative lengths of these two chapters within the study.

6.2 Attachment, love and belonging

6.2.1 Attachment behaviours

In chapter two I outlined some of the key concepts of attachment theory stressing that these need to be used with care. In this study, the starting point for the Babas' relationships with their children is an enormous distance from the new baby and parent dyad. This is because, as noted, the children are older and with impairments, have experienced extremities of adversity in their early caregiving relationships, and as a consequence of the institutional regime have acquired additional impairments and experienced severe developmental harm. It would therefore be completely inappropriate and naive to attempt to classify attachment patterns. Additionally, such an approach would also be incompatible with the research design for this study as well as being at odds with my own epistemological beliefs. All the same, throughout these chapters I do refer to attachment theories and concepts, traditional and more contemporary, in underpinning and supporting my analysis and interpretations.

In chapter two, I outlined the basics of Ainsworth's study around separation and the secure base. Aware of Schofield and Beek's (2005) point about the challenges of using secure base concepts for older children, and being particularly mindful that the children in this study have impairments, I was cautious in my interpretations but I did identify a number of proximity seeking behaviours and signals of distress upon separation. These behaviours demonstrate the potential beginnings of attachment relationships and the use of the Baba as the 'secure base' (Bowlby, 1988, 1989). I also noticed 'behaviours' that suggest levels of trust, understanding and attachment were building up between the children and their Babas. The significance of this as a 'starting point' is captured by psychologist Todor in the following interview extract:

T: The Baba is to create an emotional connection that includes trust with the particular child.

L: Is that important?

T: The most important... the individual who builds the emotional connection, she has the leading role. This isn't an obstacle for the rest of the people, the specialists, to work with the child. So, what really has happened?! Through the first emotional connection, it has been aided to be built various other connections and types of behaviour.

The Babas' interviews provided considerable data regarding how their affection for the children was demonstrated and a range of attachment associated behaviours were also evident from the children's actions. Insights and observations linked with the two key areas of separation and reunion that appeared in Ainsworth's study and later 'strange situation' research (Ainsworth et al, 1970; Ainsworth, 1978). Some of the comments from research participants also implied the children experienced distress and anxiety, and exhibited 'proximity seeking' behaviours, upon separation from their Baba, just as my observations had. This serves to confirm the beginnings of the development of attachment with the Babas. For example, Baba Elisaveta explained how Nikolai cries at the end of their sessions:

But Nikolai is now crying, he stays on his cot's wooden bars and is looking all the time for the people passing nearby. And from staying for so long on the cot's bars, he has now a little red mark here (points at her forehead)!

Baba Elisaveta

Further, observations of the children's behaviours upon reunion with the Baba at the beginning of each session demonstrate that they are learning to trust that the Babas will return. This is a notable aspect of Baba Rositza's description of Desislav when he sees her:

He is very emotional, very happy. From the moment he sees me, he stands up in the cot, he is holding to the cot and is laughing. Well he (Desislav) stretches his arms, then he is crying and he wants me to take him again. He likes to give my hair a gentle caress, also on my face, and he grabs my hair he touches his cheeks next to mine. His favourite is once he gets your hands, to place them over his face.

Baba Rositza

Attachment behaviours are also apparent in Todor's description of Ivan's relationship with his Baba, as this interview extract shows:

T: It's very strong. He can recognise the Baba's voice, her intentions... very strong relationship. He recognises her, he has expectations from her, and he is addressing his needs to her. He can give a hug, he can pass something to another person, and he has grown up.

L: Does he smile to his Baba?

T: Oh, of course! He can understand his Baba, he is looking for her.

Todor, psychologist

Other reunion behaviours noted by participants were the children 'screaming with excitement', touching, cuddling and laughing. Some children even recognised the sound of their Baba's steps before they saw them. The Babas used various strategies to emphasise to the children that reunion would occur, further building trust. Volunteer Rebecca recalled that one Baba sometimes helped her child to understand she would be coming back by drawing a watch on her child Michele's wrist using a pen, which served as a reminder of their imminent reunion.

These attachment behaviours can be summarised by reference to Beckett and Taylor (2010) who state that they, 'include behaviours which resist separation and signal distress, but also behaviours which attract the carer's attention in a positive way by smiling and other behaviours which bring the carer to the child - such behaviours serve as 'invisible elastic' ' (Beckett and Taylor, 2010:46). This 'invisible elastic' is evident in the behaviours noted above, as well as the following account where Sonya describes Nikolai's movements:

He is always moving with the walker towards the Baba, he is trying to reach her with his hands, if she moves then he is following her with the walker. But the happiest moment for them is when they enter in the morning and the child is trying to reach them with their hands, when the child is smiling and is looking for them just like

Baba Ekaterina right now (gesturing through the window to a Baba and child in the adjoining room).

Sonya, physiotherapist

These examples suggest that the children are learning to trust. The Babas are key to this development as they constantly reassure the children and explain to them what is happening which helps children to make sense of, and process, their experiences. However, in addition to learning to trust, the children are also developing cognitive understanding, memory and becoming able to hold an image of their Baba in mind. An excerpt from my interview with Rebecca, volunteer, demonstrates this:

L: Did you ever see or experience the Baba putting the children back in the cots?

R: The children would cry, they'd throw things

L: And how did the Baba behave?

R: They all behaved in different ways, some of them would blow kisses, try to settle them, say 'caio caio'

L: Did you observe any other people in the orphanage doing that with the children?

R: No. No. Just the Babas.

Having established that attachment behaviours are evident amongst the children and their Babas, and that they lead to other development, I now move onto another related theme which is inseparable from any discussion of attachment, that of 'love and belonging'.

6.2.2 Love and belonging

As discussed in chapter two, children in institutions lack the psychological and emotional investment which typically comes from parents in a family context. This absence is the most damaging factor of institutional care (Dozier et al, 2012; Nelson

et al, 2014). Consequently, emotional investment was at the forefront of the development of the Baba programme and seen as central to their role. As explained by the lead psychologists:

well the Babas are not specialists , they are not professionals, what the Baba can do is form a bond ...

Ana, psychologist

the Baba is to create an emotional connection that includes trust, with the particular child.

Todor, psychologist

When asked her understanding of how the children appear to develop and thrive from having a Baba, Kalina answered without hesitation:

Affection. Attention. Hugs. This project is really a psychological project, because actually, once the emotional bond between the Baba and the children has been established the child starts improving mentally, it's more the enthusiastic; prepare to open what the world offers him. You know, these walks, the Baba talks to the children, reads fairy tales, tells them stories of their life, of children back home, introduce them to her own grandfather, to her grandchildren, to the neighbours, and the children start developing. These are social skills, and socialisation, people develop, and love and affection is an incredible thing.

Kalina, NGO

Kalina's account captures the holistic essence of the Babas' role and highlights once more how it is difficult to separate off one aspect of caregiving from another. Bearing in mind that the primary objective of the project was to provide disabled children in Institution X with the love and affection that had been missing from their lives, it is not surprising that all of the respondents spoke of affectionate encounters between Babas and children as a key feature of the Babas role, and viewed the Baba as a source of love for the children. As observed by one volunteer, Rebecca:

I thought there was a good bond between the Babas and children. Babas offered them interaction, stimulation, they both loved each other. For the children it was definitely their source of comfort and hugs and a lot of hugging and carrying where you would never normally get that if you didn't have a Baba.

Rebecca, Vol

Similarly, Bev's recollection of one child's behaviour on two subsequent volunteering visits captures the affection and warmth in the Baba and child relationship. This example also reiterates the points made above about trust in that the child expresses his distress about separation, whilst at the same time starting to understand that his Baba will return:

One boy, all the time, he just stood alone in his cot. Every time I went to his sector he was standing up reaching out over his cot making a noise, shouting, but not words. He just stood all the time. I remembered him because he never ever sat down, unlike the other kids who were always just lying there. No one acknowledged him or stopped to talk to him. When I went back the next time (referring to her subsequent visit to the institution a few months later) he had a Baba, and he really loved her, he used to touch her face and stroke her hair, and she used to talk to him in a very calm loving voice and stroke him, he used to get out of his cot and I noticed he could walk with her support. When she had to leave him she would explain to him that she was going and he used to cry after her but he would settle.

Bev, Vol

In another comment, Susan drew from her memories of many conversations with the Babas, noting their expressions of affection. She said:

when you talk to them about the children their faces light up and there is great affection there, and the young babies, they kiss them a lot and not so much with the older children... it's not all over the place, but the affection and attachment is there.

Susan, NGO

She provided a specific example to illustrate this, commenting on the warm interactions she had observed between Hristo and his Baba:

and we just noticed lovely little things, I mean I remember Hristo who was only this little thing despite being ten, I remember all the time I was talking to his granny, we were talking, he had his mouth on her chin the whole time so we noticed they had become more tactile.

Susan, NGO

A key theme that emerged from all research participants' interviews was the reciprocal 'sense of belonging' that each Baba/child relationship appeared to have developed. I

consider this in relation to the child here and return to it later regarding the Baba. This represents an ideological shift in identity of the child, from one who 'belongs to the state' to one who 'belongs' to their Baba. One signifier of 'belonging' immediately evident in analysis of the data, was the frequent use of the personal pronoun 'my', which was present in all Baba transcripts (my emphasis throughout the following examples). For example, Baba Rosa said of Rumen, 'he makes me very happy, he is *my* favourite, although I love *my* other child as well'. Similarly, Baba Elisaveta said, 'I care about *my* children with great pleasure and lots of love' and Baba Margarita's expression linked belonging to cleanliness and presentation, 'I like *my* children to be good looking'. Another example occurred when Baba Violeta, talking about behaviour management, also expressed her 'ownership' of Penka:

Oh! However, I love her despite everything (smiling) but she understands when she is doing something and I tell her "No *my* child". For example when she is pulling the hair of some other child and I tell her "No, Baba doesn't like what you are doing".
Baba Violeta

What Baba Violeta says, and shows with her smile, also implies the presence of unconditional positive regard, which, as noted by Taylor (2012:134), is critical to the sense of belonging children need to feel, even more so if they have experienced adversity in their early relationships. Likewise, Roberts (2002:6) notes that being accepted, even when they are presenting challenging behaviours,

'is important for all babies and young children, and the bedrock of confidence that can develop as a result is crucial for those children who have a growing awareness that they are different from others. This may be because of an impairment, or because they happen to be in a minority in some way.'

Participants also noticed the manifestation of 'belonging' in other ways, for example Babas identifying similar characteristics in themselves and 'their' children. One of the volunteers recalled a conversation with Baba Violeta (with an interpreter present), noting that:

she (the Baba) was telling me about when she first saw 'her child' lying in the cot. She said she looked at her tiny, frail body and thought 'I can't do this' but then when she went home she couldn't stop thinking about her and her big sad eyes, and she thought 'this child needs me'... four years later, you can see how much they love each other. The Baba was laughing and told me 'we were made for each other... she has one tooth, and I have one tooth'... the whole time she was speaking to me she was holding the child's hands and the child was looking up at her, and I did think to myself, well, they could be a real grandma and granddaughter.

Bev, Vol

Building on this, some participants also noticed similarities between the Babas and their children that seemed to have developed during the course of their relationships:

she (the child) was always beautifully turned out and what I noticed was she developed some of the characteristics of her granny. She became quite funny, and her granny had a reputation of being quite 'snooty' and you know then Michele developed that herself, you she was very discerning about who she would be with, and so would the granny, you know.

Susan, NGO

Another example of this was shared by Ana, the psychologist, who smiled as she identified similarities between Baba Violeta and Zina as she informed me of the child becoming more vocal:

because her Baba is very talkative she keeps talking all the time which sometimes is good and sometimes is (laughs) too much...she (child) vocalises very well, it sounds almost like her Baba talking (laughs), it sounds like she is trying to tell you something like 'da da da da da da' and it keeps going (laughs) until she is tired.

Ana, psychologist

There are other subtle indications which imply a sense of 'ownership' of the child, often linked to a sense of pride in their 'achievements' as caregivers. Conversely, some children developed feelings of ownership of their Baba. This mutual sense of ownership implied a shift of understanding for both participants and represented a positive movement towards de-institutionalisation. For example, ownership was

mentioned by Baba Ekaterina when speaking about her child's reaction at the beginning of each session:

Yes, she is very excited, sometimes she can even recognise me from my steps. If some other Baba is entering the room, she immediately asks her "where is my Baba?"

Baba Ekaterina

This sense of ownership and belonging to the Baba extends in some to jealousy should the Baba give attention to other children. This was acknowledged, often with some pride, by the Babas, as they felt it reflected their care and connection with their child. For instance, as Baba Vera noted about Penka, 'She is very jealous of me when communicating with the other children'.

The psychologists and physiotherapist also observed and commented on the sense of belonging, and the sense of pride that the Babas seem to develop around their children. This took several forms, but was seen as especially important in relation to small but significant steps in their development. One of the psychologists argued that the bond between Babas and children was made manifest in their pride when the children made progress. She also told me that the Babas could become very animated, and at times a little competitive with each other (in a friendly and supportive way), regarding their child's achievements:

oh yes, they become very bonded with the children, and umm you know they keep talking about 'oh my child did this today and they didn't do that before' and 'oh I said this and they said that' and ... they are very happy with what they do.

Ana, psychologist

This sense of belonging, the bonding and the sense of mutual ownership and pride all served to create conditions supporting the de-institutionalisation of the child. As Levett-Jones et al argue, belonging 'exerts a powerful influence on thought processes, emotions, behaviour, health and happiness. People deprived of belongingness are

more likely to experience diminished self-esteem, increased stress and anxiety, depression and a decrease in general well-being' (2008:316). Experiencing 'belonging' is therefore 'fundamental to humans' (Taylor, 2012:135), and is critical in a child's development of who they are and what it means to be human. For children growing up in a total institution which encourages, reinforces and provides only for a collective identity, and constructs a sense of belonging to the state, the staff or the actual building, all of which are 'detached' from the child, a sense of belonging to another human who cares is even more vital. Such a relationship minimises the emotional distance between caregiver and child in an institutional context and minimises the risk of abuse of power (Olli et al, 2012). This sense of belonging can only develop from a foundation of connections with others who genuinely care about them. Todor (whose interview contained the comment that became the title of this thesis) reinforced the importance of the child's new 'belonging' when I asked him what he felt was the most beneficial aspect of the Baba project, arguing that:

the main thing is that this child becomes somebody's child, becomes a child to someone, the Baba's child, the child of the program... This is the first guarantee.... the first guarantee for the child to leave its anonymous identity, to become somebody's child, and for somebody to recognise this child.

Todor, psychologist

In Todor's explanation, the act of belonging, then also acknowledges the child as 'known', shedding the anonymity of the 'total institution'.

As well as noting displays of affection and signifiers of 'belonging', the Babas themselves frequently used the word 'love' when talking about their children. For example, Baba Elisaveta said, 'I care about my children with great pleasure and lots of love'. Feelings and expressions of love were also present in their concerns when asked about their children's futures. For example, when asked 'what is next for this

child?”, Baba Violeta answered, with tears in her eyes: ‘I am worried, very much. If I was younger I could take her with me, I love her’⁹.

Baba Violeta also expressed her love for another of her children who had since been adopted internationally:

I loved her so much but she was adopted, and I was crying, crying a lot after her, but although she left I am happy for her because now she has found her own home and will not grow up in the institutions.
Baba Violeta

Another Baba, Margarita, also exhibited a level of attachment to one of her children much stronger than that typical of a professional relationship in a childcare setting. Nikola was also adopted internationally and in her reflection on her relationship with him, and parting with him, Margarita said:

Nikola made me cry a lot, and months after that he was in my dreams. It was the most difficult to separate from him, I don’t know why.
Baba Margarita

These powerful assertions of love, connected with the loss of the child through adoption, may link to the love and grief that the Babas who had become separated from their blood relatives felt. In both cases, the hope that the children would have a better life made it bearable. What this strongly suggests, to return to the holistic nature of the Babas’ role and how central love and belonging were to it, is the development and building of loving familial links. Kathleen, a volunteer, commented, when asked what the Babas could offer:

they have a strong connection, not all of them of course, but most of them, they have a very strong connection with the children because they start to see them as their own grandchildren, and the

⁹ This is the intense moment I reflected upon in chapter three (pg 125)

children are starting to see them like their own grandmothers and grandfathers.

Kathleen, Vol

To label the child and Baba as grandparent and grandchild implies a personal, not professional relationship. That this is commented on by observers as well as the Babas themselves offers evidence of a change in understanding the institutionalised child. For example, Susan also identifies the Baba programme as a type of replication of a family around the child, commenting that:

You know it's really about trying to replicate what they should have had if they had a family but children only need a little amount of love and then they really start to blossom and then what happens is the grannies start to love them more because they say you know, 'my ones walking now', 'oh really?', well mine is talking' and its lovely, and they get a bit cheeky with the grannies you know, they might be seven and replicating the behaviour of a two year old but it's still progress as far as I'm concerned.

Susan, NGO

The importance of feeling part of a 'family' and experiencing 'family type' relationships, for a young child, no matter how that family is constituted, is recognised by David et al (2003:69) as especially important during times 'when families are fragmented and isolated for many different reasons'. The importance of 'belonging' was also a key theme emerging from the analysis of findings in relation to the Babas. It seems that the positive benefits of being part of the programme were wholly reciprocal. This was evident in the responses the Babas gave me when I asked why they took part in the programme. Some of the Babas reported that their own children had left home and moved far away, something which left them feeling lonely and without a cause or role. For example, Baba Elisaveta, who told me she has great-grandchildren of her own, expressed both how lonely she had been since her family had moved abroad and what the Baba programme had given her:

I miss my own grandchildren and these children just help me to fill this emptiness. I benefited a lot, and this is not in the financial part. When I mentioned about my children, and the fact that they went abroad, I was under huge stress. I missed my grandchildren so much, because I used to take care of them, so I was so stressed when they were not here anymore. So when I started my job at the orphanage, these children helped me to relieve the stress. This job came in a very good moment for me.

Baba Elisaveta

Similar feelings were also expressed by Baba Petya:

If I have to stay home instead I will not have the chance to communicate with the children, to meet them, because my grandchildren are adults, they are 22 and 18 years old and we are alone, we are just two of us

Baba Petya

Not only did the Babas express their appreciation of 'belonging' to their children, other participants highlighted how they witnessed the Babas developing strong and supportive connections amongst themselves. Kalina, for instance, recognised the benefits to both parties in combatting isolation:

because I realise being lonely can kill you no matter if you baby or adult and so the programme prevents both ages to be lonely from loneliness.

Kalina, NGO

These benefits to the adults was also replicated in other Baba programmes. Speaking about a programme located in a different institution, Elena highlighted the social aspects as significant for the Babas as well as the children. This was reflected in her response to my question about what the strengths of this type of programme were, where she said a major factor was:

Because this is a project which concerns two marginal groups of people. The old people who are retired, and they are lonely as well,

as their children have grown up, leaving them with no one to look after them, living on a very small pension, so even being paid was a great help to their small pension, and the Babas themselves, they set up a small society, and they felt very happy, they would drink coffee together, they would take the children out together, when they were finished with the children they would go out together, you know, they set themselves up a very social circle, they would take the children for coffee in the centre of the village.

Elena, NGO

Todor also noted that feelings of well-being for the Babas were a strength of the programme. He related this to positive self-esteem and a sense of belonging (Levett-Jones, 2008),

yes first of all, all these women are women who have gone into pension and in psychology of the pension is I'm not useful anymore, and I'm finished and no one will acknowledge what I'm going to think, and this makes them feel useful and positive and keeps them busy and that's good for themselves, it's important for their growing older.

Todor, psychologist

Having explored aspects of the attachments developing between the Babas and their children, and the positive consequences of these changes regarding belonging, ownership and love, particularly in relation to the child's emotional development, but also for the Babas, the following section moves on to consider how this supports the child's developing sense of self and identity.

6.3 Becoming a Person

'the children think they are the cot'. Susan, NGO

In one of my diary entries (Appendix 1) I pondered a question about one of the babies in Area A. A young volunteer, who had spent a lot of time caring for this baby with hydrocephalus, a child who was never held by anyone else, asked me 'did it mean he

existed because she had held him every day during her volunteering period?', so engaging with concepts of selfhood and identity. In another diary entry (Appendix 1), I reflected upon my shock when I came upon an 'unrecognisable' child. This child looked and 'presented' completely differently to the one I had met on a previous visit only three months earlier. In many interviews, the significance of the Baba (like the young volunteer) as a means by which the child develops a sense of who they are, or a 'sense of self' was mentioned. This is shown in Susan's response to my question about the Babas' role, which took the situation before the Baba programme, when children were rarely lifted from their cots, into account:

the main roles are to give that child a sense of self just as they would with their own children, it's to help that child find out who they really are and it's through those early techniques no matter what the child's age, it's those early techniques of feeling they belong to something or to someone and to start learning a bit about themselves and doing little things for themselves. So I would say that the primary role is to help the children find out who they are and be aware that they are an individual, I mean some of these children think they are the cot! they have no awareness of what their hands are even, umm,... so lost!

Susan, NGO

It became apparent that the part of the care which involves handling and touching the children is viewed by the participants as being critical to the child's developing sense of themselves. Young children become aware that they exist, as a result of being touched, talked to and gazed at (Alvarez, 1992). It is also through this that they become aware of the human world outside of themselves (David et al, 2003). This aspect of care is critical for the children in Area A in counteracting the dehumanising environment of the total institution. Also from the interviews it was established that the typical routine at the beginning of a session with the Babas would be to bathe the child and, once clean, the Babas would dress them in the clothes they had brought from home. At the end of a session together, the Baba would dress the child in the institutional clothes again and take their own clothes home to be laundered for another

day. Goffman (1961) refers to 'mortification processes' whereby an institutional resident is stripped of their previous 'individual' identity upon admission to the institution. The Babas appear to be performing almost a reversal of this process. Having been in the institution since birth, the children's usual presentation of self is the 'institutionalised' one, as the children in Area A do not have any signifiers of belonging or identity to be stripped of. In an informal conversation with volunteer Bev, one of the research participants, she reminded me that the children in Area A did not even have names displayed above their cots. This was not the same for the young children in cots in other areas of the institution whose names would at least be displayed alongside their dates of birth. This notion of the 'institutionalised self' also incorporated the anonymous clothing worn by the children. As Ana said:

Because on the ward, you know, you put on the first thing that comes to your hand. So, there is really no "this is Denis's cupboard, and this is Yordania's cupboard, and this is... ", you know. They haven't got any property.

Ana, psychologist

In contrast to this anonymous and communal wardrobe, instead emphasising both belonging and individuality, Baba Ekaterina told me she brings in clothes from her own granddaughter, which suggests she is giving her child the same status as a child of her biological family. Affording the child this status implies 'like us', a position which facilitates intimacy and closeness rather than taking a segregating position of 'not like us' (Davis, Watson and Cunningham-Burley 2000, cited in Olli et al, 2014). When I asked her why she did this, she answered, 'Well because I want them to be better dressed and looking good'. Dressing the child with consideration of how they look to others was discussed in chapter five in relation to cleanliness, presentation and looking 'normal'. It is also tied into the Baba's knowing that this would be more likely to elicit a positive response from other people and that they would be seen more as people in their own right.

This consideration of the child as individual is antithetical to large scale facilities like Institution X, which are characterised by 'batch rearing' practices. These are marked by an inappropriate lack of privacy for children, especially in bathing and toileting areas. As a visitor/volunteer it is common to see rows of younger naked children on potties, or to hear stories of large numbers of older naked children using group showers. In Area A, the bathing areas are in open spaces at the sides of each large room. This assumes invisibility and shows a lack of respect for the child as an individual with a right to dignity and privacy. In accounts of institutionalised disabled children this lack of privacy is reported as adding to other risk features of large scale institutions, making the children more vulnerable to sexual abuse (Conroy, 2014; Stanley et al, 1999, UNCF, 2007). The Babas programme in contrast, reasserted the importance of privacy and individual identity. This was noted by Susan when commenting on Michele's developing awareness of her own boundaries since having a Baba:

One of the things I've noticed is that she was being changed when she was about seven in front of all the carers, and she was unaware and she would be waving, and she wouldn't care about being naked, whereas now she is very aware, and aware of her dignity and would say 'no'.

Susan, NGO

Whilst this presents evidence of Michele's developing identity as a girl establishing her understanding of personal boundaries and her need for privacy, it additionally emphasises the significance of the Baba's role in making the child less anonymous. Susan's conviction that Michele will now object to a lack of privacy suggests how her developing identity could also serve as a protective factor in future.

Mulheir (2012) notes that communication difficulties often get in the way of children disclosing abuse. Michele's Baba, in getting to know and understand her, can also offer protection in this way as these expectations of privacy have come from her Baba.

Another aspect of Michele's developing sense of self and identity, supported sensitively by her Baba, is in relation to her new gender identity as a girl. In interview, Todor selected her as an example of a child who had benefitted most from the Baba programme due to this gender-related support. He explained:

Michele was in two parts, I mean as an identity, she wasn't Michki (Bulgarian shortening of the female name Michele), she was Michel. This was the typical way the employees were seeing her. They were accepting her as a boy, you know she is transgender. She was somehow divided in two.

Todor, psychologist

He went on to explain that after the medical tests and the decision that she was to be raised as a girl, the Babas and the staff of the Baba programme made a great effort to support her with this transition:

L: Does Michele understand, have the people explained to Michele what's happened?

T: Yes, after it was made clear that she is a girl, the Baba was addressing her like a girl, as well as the personnel. We want to say that she was prepared for this because we often were telling her "you are a little pretty girl, you are this and you are that".

Todor, psychologist

Baba Ekaterina was critical in this transitional process, both as a mediator of the involvement of others around the child, and as a female role model for her. It was obvious that she realised the importance of her role in supporting Michele's developing identity as a girl, which she appeared to take great pride in. She told me:

Well you can see, she copies everything from me, and what I am doing. I taught her to be a very clean girl, she is always dressed with very pretty clothes, and she likes it... , now she likes her hair to be gathered on a pony tail on the top of her head.

Baba Ekaterina

Despite my reservations about terms like 'gender appropriate' as potentially curtailing individuality, and in contrast to my own philosophical position on gender as primarily

socially constructed. I endeavoured to view this transition in relation to the cultural specificity of this study which influenced my interpretation. This interpretation also raised other issues for me around the medicalisation of Michele's body which I discuss in section 7.4.

Dressing the children in 'gender appropriate' clothing and accessories was perceived by research participants as significant for the children in terms of their developing identities, their individuality, but also as a means by which Babas demonstrated their love for the children and their pride in their role as primary carers. Jane illustrated this when noting the differences between how the nurses dressed the children compared to the Babas:

There'd be stocks of children's clothes in the cupboard, and you'd see the nurse come in and just pick the first one out... whereas the Babas took so much care in what they gave them, how they dressed them... they'd plait the girls' hair... they'd bring clothes in for them, just the pride on their faces. I remember how this one lady had got a little girl dressed in a lovely dress, and then put a bobble on the top of her hair and it looked absolutely ridiculous (laughs) but the pride in the Babas face was like 'I did that, that's my child', and then they'd go out in the village and stuff. For the nurses it was more about ease for them. Their clothes would have holes in, they wouldn't fit them properly. I know in Area A they all had these generic fleeces they got put in, in winter... Things that tied on their shoulders. They didn't want the children to get out of them so they'd tie them really tight and some of the kids had sores on their shoulders. With the fleeces, one of the kids kept on taking his nappy off, and so they'd been put in this onesie without a nappy on and her feet were drenched with urine...Whereas the Babas would come in with their own little clothes, and nothing of these things that tie at the shoulder. It was always they wanted the best for them, like any mother or grandmother would.

Jane, Vol

An appreciation of the developing identity of their child was also apparent when the Babas noted the likes and dislikes of their children, often commenting on their 'little ways'. In doing so, they demonstrate that the child is no longer anonymous but a person with unique characteristics, temperament and traits, again something related

to the concept of unconditional positive regard (Rogers, 1965; Taylor, 2012). The child learns that their identity, the person they are, is visible, noticed, understood and loved for who they are. Of course, this also indicates de-institutionalisation even within an institution. A comment from Baba Elisaveta, for example, stood out to me as demonstrating acceptance of Rumen as an individual, and in doing so also challenging many aspects of the 'total institution'. Smiling affectionately, she told me about Rumen and his 'tantrums':

Well, if Rumen for example doesn't like something, you know him, how he steps on the ground (my interpretation 'stamps his foot') and doesn't like it, then I wait for his bad mood to go away, usually he stays for some time and then he tends to forget, and then we continue. I have never forced him to do anything he didn't like to do.

Baba Elisaveta

Here Baba Elisaveta is taking time to support Rumen's emotional development, allowing for his 'bad mood' and loving him regardless. She is also supporting the development of his emotional regulation, which is critical in emotional development and in building his self-esteem (Taylor, 2012; Maginn and Cameron, 2013). He is being noticed and understood as an individual despite the institutional context where his needs are usually addressed within a rigidly structured routine and expressions of temperament and self are not welcomed. She is encouraging him to make decisions and choices and in doing so she is supporting his developing sense of agency (Olli et al, 2014) and enabling him to be a competent child trying to assert some control over his own actions. Rumen's actions, stamping his foot and standing still until he is ready to move on, also suggests he feels he has some power in the relationship, and that he is beginning to view himself as being able to control the outcomes of others. This seemingly small example illustrates a significant shift in Rumen's developing identity.

Beazley and Williams (2014), note the role that adults play in the way they relate to a disabled child and how this influences the child's perceptions of themselves. In

describing their children to me, Babas noticed and responded to difference positively, and typically commented about their children's differences with affection. One example is how Baba Rosita describes the various ways in which her children like to be held:

Well for Desislav, the best thing he enjoys is the bathing definitely, and to have the physical contact. Ivan likes me to hold him and move with jerky motions. He doesn't allow me very close for things like hugs and caress, he like to keep a distance, he is a bit different.

Baba Rositza

In her comment, 'he is a bit different', I understood that Baba Rositsa is referring to the autistic behaviours this child displays. She does not present this as negative or deficit on the part of the child, rather she is explaining how she understands the differences between her children, which reflects her assumption that it is her role as their carer to adapt her caregiving routine and skills in order to meet their individual needs. This narrative rejects the limiting tragedy and medical models of disability which are common regarding disability in Bulgaria (Russell and Smirnova, 2014). It is interesting in terms of identity that none of the Babas spoke about the child's impairment other than very occasionally and briefly referring to some aspect of the potentially restricting impact (Thomas, 1999). For example, when Baba Elisaveta spoke about Nikolai having to develop strength in his arms (in chapter five), she didn't state as problematic or 'tragic' that Nikolai doesn't have legs, nor did she adopt a pitiful tone in expressing this. Her seemingly 'matter of fact' attitude presents a view of Nikolai as a competent and resilient child who, with support from herself and an enabling environment is capable of developing his own strategies for getting around. This presentation of Nikolai is in contrast to typical understandings of disabled children as passive, helpless and dependent (Russell and Smirnova, 2014, Connors and Stalker, 2003).

In most interviews the child's identity label as having Down's Syndrome, Cerebral Palsy, growth hormone deficiency or any other 'impairment label' was not mentioned by the Babas. They appeared to be well attuned to understanding the children's poor health and developmental harm as a result of a lifetime of institutionalisation, rather than as resulting from their impairment or medical diagnosis. This is aligned with a social model approach in that they recognise it is the institutional regime that has significantly hindered the children's development (Music, 2011, Olli et al, 2012). This is unlike the approach of the staff who appeared to limit their understandings and expectations of the child according to the 'medical diagnosis' even when evidence is presented to the contrary (as noted by Susan in chapter five). This could lead to tensions between perspectives, and action being taken on behalf of their child by Babas. For instance, Baba Elisaveta provided an example of how she challenged medical model expectations for her child with staff in Area A who thought Rumen would never walk or talk. At the beginning of the quotation she is also demonstrating a social model understanding by recognising the disabling barriers of the institution in restricting the free physical movement of the children:

This program helped children with disabilities that cannot move, this program helped the children go out of the institution. Now these children can move with legs and arms. So it is very important. When I first let Rumen walk in the Area A and was telling the staff there that he is walking now, I went there and said "Rumen is walking", so they were very surprised. Me and Rumen we were at the door and then I let him walk alone, and he start walking, so everyone was like "Ah!". At the beginning he couldn't talk. Even the staff were telling me, they were thinking that he will never be able to talk. Now he can say "let's go".

Baba Elisaveta

She told me that when she is out walking with Rumen, 'When he sees people he smiles at them, and they do it too, also he like to send them air kisses'. This description of Rumen is indicative of her encouragement and how it is helping him to develop a sense of himself as a child worthy of receiving love and affection back from others,

thus challenging negative perceptions. The act of 'blowing kisses' is usually with the expectation that someone will respond with an 'air kiss' too. Rumen is a child who looks distinctive as he has a growth hormone deficiency which means he is very small. The Baba's expectation that the community will welcome him and respond to him positively is giving a message to Rumen that he is a child, just like any other child, and deserves to be responded to as such. The Baba's expectations for Rumen are being made visible in the community around Rumen which has potential to influence changes in expectations of others. Rumen's developing sense of agency is also evident in the direction he offers to the Baba when he says 'let's go'.

In chapter five, it was evident that the Babas 'noticed' and 'knew' their children. They easily recalled their children's ages and some offered birth dates when I asked how old their children were. Other events were also remembered, some of which are significant here, as when Baba Elisaveta surprised me by recalling the date that her child started to walk. She offered without hesitation, 'he was first walking on the 21st November last year'. The Director of Institution X shed light on the significance of this example, indicating that it positioned the child at the centre of a group of people who were sharing a cultural tradition, this reinforcing the importance of children's development in a cultural context (Rogoff, 1990; Super and Harness, 1986; Packer, 2017). She explained that:

even a small step forward is celebrated every day for such a small child, all the Babas rejoice about that child's progress... if a child who was bedridden and could not walk starts walking there is a Bulgarian tradition when the child starts walking they make a loaf of bread (brief pause), and everybody takes a bit with salt and with honey and we wish him luck or different things, and every Baba does this for every child.

Elitza, Director

This suggests that the child's newly developing identity is one that is not only connected to their relationship with the Baba, but also a wider group, where they are

appreciated and engaged with positively by others. The examples suggest that the children are starting to gain positive responses and messages about themselves from the community both within the institution and (for some children) outside in the local community, thus contributing to and strengthening a positive sense of self. In turn this contributes to the strengthening of the ecology of the child by increasing the caring connections around the child which has been established as significant for children's development (Bronfenbrenner, 1979, 1986; Swick and Williams, 2006).

During my visits to Institution X, and in many interactions with the Babas, I noticed how they looked after each other's children, reflecting the notion of group and community belonging for the children. On one occasion when I arrived with a suitcase of hand knitted items the Babas not only selected items for their own children, but pointed out items to other Babas that would fit, or suit, their children. During my interviews with Babas they made sure one of their 'friends', another Baba, was looking after their child while they were taking part in the interview. This notion of community is very evident in some notes I had written about an incident one time in the Baba playroom. One of the Babas wanted to show me how her child, Hristo (who I had met on previous visits), could now walk. Whilst this was not one of the Babas that I interviewed as she hadn't been available at the time, this incident is significant in illustrating the child's belonging to the group of Babas. All of the other Babas were smiling in agreement while she told me the story through the interpreter. Urged on by the other Babas she took Hristo to the walking frame that was positioned along the furthest wall and helped him to hold on to the bars with his feet firmly on the floor. The other Babas all started to cheer him on as he worked his way along the wall, smiling as he walked. His Baba was next to him the whole time, walking slowly by his side and using words and smiles to encourage him along. Here, the Baba is acting as reference point or 'safe base' (Bowlby, 1969). When he got to the end all of the Babas clapped and smiled, as did I and the psychologist attached to the programme.

These examples serve to suggest that having a Baba affords the child a stronger sense of belonging within the community in the institution, rather than to the institution. Interestingly, although I hadn't interviewed Hristo's Baba, his name also cropped up during my interview with Susan, NGO, as she selected him as an example of one of the children who had benefitted most from having a Baba. Her explanation also highlighted the way the Babas enjoyed celebrating their children's achievements:

S- I would say Hristo who has Down's Syndrome and he was just lying on his back

L – how old was he ?

S – he was 9 and he had a slight squint in his eye and this vacant look, I mean so he looked completely gone, and umm when you picked him up he was just a bag of bones and you could tell that his bones were rubbing against each other. He was sore and his knees were so sore and I don't know if (pause), I thought he was gone, you know?, if it's too late because of his age, and umm we matched him with a granny who had been a music teacher, she was very gentle and she just used to sing to him, and he now has the most amazing love of music. Now anytime he hears any music he gets up to dance you know he loves an audience, he's our star performer, he gets up and walks and is very confident

L – after how long

S – he was our first intake so October 2008, and he was able to stand and walk with support 3 years later, and he is now walking independently on his own. He's physically so changed and he has grown about a foot so he still looks about 4 and he's 14, but he has an enormous personality, and is going to be adopted, and he will talk. If you say to him 'who's your baba?' he points her out, and I think his speech will take a long time but I think he will get there.

When Susan describes Hristo as the 'star performer' I recall an image of the Babas' playroom and how the Babas would gently encourage the children to 'perform' for the other Babas, children and any visitors. This narrative flags up another aspect of caregiving behaviour that supported the children's developing identities as it reflects the conclusions of a small study by Boyd Webb (1984) cited in David et al (2003), which identified 'bugging and nudging' by parents. This encouragement was found to be helpful in supporting the child's developing self-assurance and confidence.

Interestingly, the two other aspects of parenting which they found to contribute to the child's emotional development in this way were the use of pet names and respect for children's own identification of routines that matter to them; both of which were also evident in the findings. The Babas often used shortened versions of the children's names, for example Lubomir becoming Lubcho, and they also showed respect for what the children liked to do as 'special' or 'treasured' part of their routines, for example Michele's drawn on wrist watch.

Another impact of the children being considered as individuals and cared for by the Babas was a ripple of consciousness of the children as people amongst the staff, themselves often institutionalised. Staff were noted as taking more interest in a child through the intervention of their Baba. This was evident when Baba Elisaveta was talking about Rumen's achievements being celebrated by the staff in the institution and also when Babas spoke on their child's behalf. Todor acknowledged the positive effects of having a group of people in the child's life with the Baba as the key facilitator of relationships. Although he says they are not replicating a family in the institution, his comments do suggest that, like a family, people do have specific roles. Using the example of Michele he explained:

what I mean is that she can behave differently with the different people and to have totally different development. That means with her Baba she is behaving in one way, with Ana (psychologist) in another way, with Sonya (physiotherapist) she is different, and with me she is also different. We can explain that with some examples: she wants one person to hold her, another to feed her, with the third one she wants to watch something. This is not a replacement of the family structure, but this is human behaviour which allows her to have all these activities. The same can be addressed to the volunteers because with them she was playing in a different way. The whole program allows this place to open up, and to open up for the child a new environment which helps the child to be recognised, to be respected, to be supported.

Todor, psychologist

The next section of this chapter considers how the children use their newly developed trusting relationships with the Babas as their 'safe base' from which to explore their world, thus encouraging their development in all areas.

6.4 Exploration from a secure base

'He only knew before the ceiling above him'

Baba Elisaveta

The concept of a child's attachment figure, or figures, providing a secure base from which to explore the world is one of the central tenets of attachment theory (Bowlby, 1989; Ainsworth, 1978; Tharner, 2011). As explained in chapter two, a child will have the confidence to explore knowing that the secure base, the attachment figure, is available for the restoration of safety if required. Variations on a 'secure base', or of having a trusted person to 'stand beside', as a safety net, were central to research participants' responses when asked about the benefits of a child having a Baba. This provides opportunities to explore and play in a safe and secure environment – and, in turn, has an impact on children's mobility and movement, which are important for their development (O'Connor and Daly, 2016).

For the children in Area A, participants noted that before having a Baba the children rarely left their cots and never left their rooms. The new Director said;

What I can confirm is that the children saw a different approach because at that time they were very rarely taken out of the building least for a walk... because the children used to live in their rooms, behind four walls, they were not even moved from one floor to another floor. They stayed only behind four walls, they would see only the room, they were taken out and they would only see the trees from the room.

Elitza, new director

For these children it is understandable that, consequently, the 'bigger world', whether outside Institution X or even simply outside Area A, could be a frightening place. However, as demonstrated in this chapter, the Babas' caregiving practices laid down the necessary foundations for this 'next stage' by building up trusting relationships with the children and 'being there' for them. Bronfenbrenner (1979) notes that a child's development occurs within an increasingly wider world and the reciprocal interactions. This was evident in Babas' responses when they told me how they spent their time with their children. A typical daily routine, in addition to the physical care routines outlined in chapter five, would include a visit to the 'playroom'. This is quite a journey as it involves venturing down long bare corridors, and using an old lift or concrete stairs to travel the four storeys between Area A and the ground floor. Further, not only did Babas take the children out of their cots and out of their rooms but they also took them into the local community around the institution, this experience often being the first time the child has been outdoors. The Babas are therefore physically expanding the children's worlds. In doing so, as is suggested by existing research and theory presented in chapter two (Bornstein and Lamb, 2012), particularly the individual and social constructivist perspectives of Piaget and Vygotsky (Smith et al, 2014), it is inevitable that the children's learning and development would be increased by these new opportunities.

As established in chapter two, regardless of cultural differences, and underpinned by key theoretical traditions (Bornstein and Lamb, 2011), three main factors are critical to children's development; trusting relationships, opportunities for exploration of objects and environments, and culturally mediated activities. From the security of the trusting relationships developed with the Babas, (outlined here and in chapter five) the children were able to experience the world themselves through their own senses in order to make meaning from it. Baba Elisaveta offered a lovely example of this when she told me about her children, Rumen and Elenko:

When we are out with Rumen, we are watching the cars, observing the trolley bus. He just started to know the outside world.

Baba Elisaveta

She elaborated on the significance of learning for the children in these new explorations of a world they have never seen, beginning with them leaving their room in Area A and then moving into the world beyond the institution:

The children have already seen this world [Area A]. The children have seen it, they have never been outside before. When I first took Elenko outside of his room, he was touching the wall like that, and he was knocking on it to see 'what is this?' He only knew before the ceiling above him. When we went out he was very interested in the cars. Initially he was scared from the cars, then what I did is to stop us near a car and start telling him about the cars, then he started touching, knocking on it. So through this they had the chance to know about the outside world. Yes, this program is very important, because before that the only thing they knew was to be staying inside, in their rooms.

This engagement with learning is also apparent in what Baba Ekaterina said about Gheorgi:

and when I get there the child can go out of this environment, to go out of the room where is constantly staying, we go for a walk, and with all this, this is making a difference for the child. This way the child has also the chance to meet other people.

Emil spoke about the importance of the children getting outside into the local community seeing it as expanding their world and experiences. However, it was not only valuable as new learning experience for them but also for the community in making visible to them the children who have been hidden away:

That's why taking the children out is one of the best things, they walking the children on the streets, they are showing the nation, they are showing the children the flowers when Spring is coming, and after that they are taking them to their own houses and shops and showing them the regular way of living not in the orphanage, because the orphanage life is different and of course of the way to their home they are meeting other grandmothers and they are sharing with them something.

Emil, NGO

The importance of making the children more visible in the community was also spoken about by one of the volunteers, Kathleen, when reminding me of earlier visits when we were asked not to take the children out into the local park in response to resistance to their presence. This is pertinent given communal stigma, shame and uncertainty regarding disabled children being institutionalised in the first place (as explored in chapter four).

but do you remember that that was also remarked upon that they had wanted to do that but there was resistance from the villages that didn't want them going to the parks? They didn't want their own children meeting with these orphanage children. So there was still a mind-set that says 'these are the untouchables and we want nothing to do with them', and that was the way it used to be. It (the orphanage) was enclosed so I think the Babas going out (pause)... if the Babas were accepted as part of the community, then that perhaps had the knock on effect of making these children a bit more acceptable ... and as the children improved, and could communicate and better dressed and then that must have impacted hugely and it must have made a difference to how they were received. It (the orphanage) was central to the village which was rare because very often they were on the outskirts or in remote parts of villages.

Kathleen, Vol

In terms of the developmental benefits of a secure base, all of the children experienced some progress from having a Baba. To return to Todor's examples of particular children who he thought had benefitted from the programme, he mentioned two different children and for completely different reasons. His first example was Ivan, whose small changes could actually be viewed as very significant given his label of autism. Here, having a secure base enabled engagement with others. Stressing the importance of the whole team around the child, Todor noted the way that Ivan moved on from communicating only with and through an object, to being able to communicate and connect with people:

Before he has got a Baba, Ivan was playing in a strange way with an autistic object, and that was all. He was just lying in the bed, eating the food and was playing with this object which is, I hope we understand, it's a cold object that he can touch, that will not

communicate with him, this object is everything, and he addresses everything. He was not interested in anything else. He was not interested in any individual's face, any individual's voice. The only individual presence for him was related to who is giving the food. All his behaviour was managed (or directed) by this object. He was slightly standing up, crawling slightly and was attached to this object... So, thanks to the Baba program, the environment, and the personnel here at the institution, Ivan made a progress. From this object, he managed to build a connection to contact with hands, with voice, with eyes, and with an individual.

Todor, psychologist

The second example Todor mentioned was Michele, a child who has already appeared in these chapters, and one who seemed to have made substantial developmental progress since having her Baba. This was not only noted by Todor, but she was also highlighted by the other psychologist, her Baba, one of the physiotherapists, one of NGO reps and two of the volunteers. Michele had developed into an individual, a social being, something perhaps suggested from the start by Baba Ekaterina, who told me that when she first met Michele she knew immediately that she would like to be matched with her. Yet, when she described Michele from the beginning of the programme, at the age of six, it was as a child who, according to her Baba, 'could not sit, she couldn't do anything, only was lying in the bed, without speech'. Baba Ekaterina, however, went on to explain that she still saw Michele at this point as a 'happy kid' and explained that when she first saw her:

she gave me her hand and smiled at me, and I liked her. Yes, when I was passing her cot she gave me her hand, even she grasped my hand. She was eating from a bottle. To help her learn how to sit we were helping us with some little chairs, but the most beneficial and helpful for her was the physiotherapy, the massages. Later she began crying for me to stay with her, she wants me to lie next to her on the cot, but isn't possible. She remembers and memorises everything, she started telling me stories, she is singing songs.

Baba Ekaterina

This account shows succinctly a large shift in terms of belonging, a sense of self and how her Baba became her secure base. It also demonstrates Baba Ekaterina's

commitment to her and her acceptance of her needs. This development becomes even clearer in other aspects of Baba Ekaterina's account. She explained, for instance, that during a typical session together, after Michele has been washed and dressed:

we go to the play room where she like to play with the toys, and is playing more and more in a very nice way. She started recognizing..., for example yesterday she was talking to the Bear "I am the mom and she is the baba". She is telling me everything what she had in the morning at school, and even if she did something wrong she will still tell me about it... Well she can remember everything, she knows almost everybody working at the orphanage. She knows the physiotherapists, the psychologists, everything, she knows everybody's name. Sometimes she chooses the food. It's important to have a baba that is taking care of the child because this kid more or less is all day with the staff at the orphanage, and when I get there the child can go out of this environment, to go out of the room where is constantly staying, we go for a walk, and with all this is making a difference for the child. This was the child has also the chance to meet other people. Michele is also feeling good because I give her permission to do things that she is not allowed all the time.

Baba Ekaterina

Michele's development provides an example of all of the conditions coming together to transform her experience of institutional life, effectively de-institutionalising her. The engagement she shows with others in the wider community, both within and outside the institution is hugely different from her initial condition. That shows the impact of the Baba programme, as the 'total institution' defined her as passive and incapable due to her impairment, met her basic needs via a harsh regime of regimented and detached caregiving practices and further impaired her potential for development by restricting her physical movement and exploration. Having a Baba has allowed Michele to be a part of a trusting relationship over a long period of time and this has set the foundations for her to develop relationships with others around her. This contrasts with the initial six years of her life, when Michele was 'parented' by the state in a large institution which cannot allow for emotional investment in the child. She now has a narrative of a type of 'family life' that she can enact with her toys in her imaginary

play. Her Baba has acted as a secure base and so opened up a new world of exploration and learning within her own cultural heritage and community.

In summary, being able to 'explore the world' was mentioned as a strength of the Baba programme not only as it brought obvious health and developmental gains associated with physical movement, but also as it challenged the local people around the institution to 'see' the children and to become involved in their lives, even in small ways. The importance of this was stressed by Baba Margarita when asked what difference the Baba programme makes to the children:

All these children that were not able to go out of their cots, it's so clear that... more or less they are socialising, and becoming familiar with the society. What can be better than this?

Baba Margarita

This movement towards de-institutionalisation, through the security offered by the Babas, and into community is also emphasised by Elena, who argued that the impact of the Babas was not only on the children, or the Babas, but on the whole village. She stated that,

The whole village starting in one way, directly or indirectly, taking care of these children of the institution, so the children you know came more social, met more people, learnt to communicate with people outside the boundaries of the institution, the orphanage. This reflects positively on them, and you could see the change almost immediate.

Elena, NGO

6.5 The Baba in Bulgaria

During the interviews I sought to understand the significance of the grandmother in Bulgarian culture. I was already a little aware of this as I had on my first visit to Bulgaria experienced an important celebration named after Baba Marta (Grandmother March)

which involves giving bracelets and brooches (martenistas) to loved ones to welcome the spring¹⁰. The celebration was included in 2017 on the UNESCO Representative List of the Intangible Cultural Heritage of Humanity (Culture Sector, UNESCO, 2017).

I was consequently keen to understand whether the programme had a specific cultural quality which I might be missing as a 'visitor'. When I asked participants to explain to me whether the Baba was culturally important, they emphasised how significant the Baba role is and that the Baba is a much respected and key figure in family life. This explanation was often accompanied by smiles and expressive and expansive hand gestures. For example, Todor, the lead psychologist, highlighted the place of the Baba in Bulgarian families explaining:

because the Baba in the Bulgarian culture (brief pause for thinking), in Bulgarian culture the Baba figure is the person who gives you all this (he stretches out his arms), all the love, all the spoiling, you know...she's the source of everything nice.

Todor, psychologist

The cultural significance of the Babas combined with the personal life experiences of individual Babas in potent ways. Todor shared his view of the Baba as a more experienced caregiver with more to bring to the child, outlining and reinforcing all of the aspects of the Baba's caregiving role that have been established in my findings and discussion. His comments, in addition, also imply a greater form of 'Babaness', a kind of positive and powerful stereotype or archetype:

about the Babas...: Hmmmmm, to answer the question "how", what is the Baba's resources? Well we can start from the simplest which is respect, then continue with the love that they receive, then all their activities, and at the end but not the last is the understanding that the child can get. Also the experience of the Baba throughout the years, the fact that they are mothers and grandmothers, the moments of playing, the way they address the child, the

¹⁰ Information gained from a Bulgarian friend during a conversation after she gave me a martinista bracelet.

communication. All those factors create this special well it is not only a behaviour, it is a special place in one child's psychology.

Todor, psychologist

This view was corroborated by Kalina (NGO) who explained that in developing the project it was important that the caregiver should be a Baba, not only for cultural reasons, but taking account of the Baba's experience, maturity and wisdom gained from years of caregiving in their own families. Here again, there is a positive generalisation of the Baba as a powerful yet benign figure which may be related to cultural influences and constructions. In referring to a pilot project (prior to the development of this particular Baba programme), she recalled the differences between the Babas and a group of Bulgarian student volunteers:

They (the Babas) were giving love (pause), you know, the students were making happy, they (the students) were saying 'ahh ahh ahh ahh' but their life was somewhere else, where the grannies were giving real life, like ladies who had been through many things and now the child was in their hands and they were in the hands of the child, you know, beautiful connections.

Kalina, NGO

Like Todor and Kalina, other participants also highlighted the importance of maturity, wisdom and life experiences of the Baba as key to providing warmth, patience and responsiveness in their encounters with the children. This was sometimes linked to historical and social constructions and models. For instance, Emil explained how over generations in Bulgarian families the Babas have cared for the children:

To have babysitters in Bulgaria that's not so popular, its , for us its absolutely normal when you want to go away or cinema or beer or something just ring the bell to the grandparents and say 'come on, here is your grandson or grand daughter, please take care of her for couple of hours.... always the Baba. I was cared for by my Baba...it was our generation and still the generation of the Babas that we use... they are seventy years old and err in their heads are still alive the story of three generations in one house and the grandparents

are raising the grandchildren and the parents are going earning the money.

Emil, NGO

Volunteers also noticed the limitations of their own roles in comparison to that of the Babas, in that they went into institutions for short periods of time and were not able to offer sustained daily routines over weeks, months or years. Nor could they communicate effectively with the children or the staff. They also considered the lack of cultural awareness in the care they offered to the children. When asked her opinion of the difference between the Babas and the volunteers for the children, Bev commented:

What did the Babas do that volunteers couldn't? 'form a proper bond' Volunteers couldn't do one on one enough to make a big difference, whereas the Babas spent time every day with the same child, they could get to know them and build a proper relationship with them, and they could speak Bulgarian- helps to develop their language skills as well as they could speak to the nurses and find out more about the children. They also felt more of a sense of belonging to a Bulgarian community, one of the celebrations – I noticed was that the Babas gave their children bracelets.

Bev, Vol

As highlighted by Wilson, (1998:92), young children are utterly reliant on 'sustained and extended interaction with a committed and enculturated care-giver.' One of the volunteers, Jane, who was at the time of the interview undertaking a degree in speech therapy, noted the importance of communication in supporting the child's understanding of their world in order to make meaning from it. She also noted the significance of the Babas in offering the children choices. She said,

Volunteers can only do so much. It's needs to be someone like the Babas taking a more dominant role. As volunteers we are only there for a couple of weeks, but the children need that continuity and someone from their own culture background, who knows the norms, someone who speaks their own language properly, like nursery rhymes, being able to explain why you're doing things with them like

why you're changing the nappy going outside picking them up to carry them down the stairs to the playroom. Just you know it just happened to them. We were trying to do the best for them but they were just passive in that situation. Passive. At least the Babas can say things like 'yes I know your bum is really sore because you've got a really bad rash but I'm putting this cream on, taking you out of the nappy, I know it will hurt but it's going to make it better, and I'm picking you up so you can go downstairs' or even just the option of 'do you want to go on the slide?' instead of putting them on and then finding out they don't want to go on and cry. Learning what they want instead of just learning by trial and error.

Jane, Vol

It is the everyday moments that matter for children's development and learning, and the caregiver's capacity for turning these events into meaningful and relational moments that is critical. Continuity allowed the Babas to be an effective agent in the emotional development of the children's lives, expanding both their sense of themselves and their understanding of their worlds. Jane's quote also sums up the cultural aspects of learning, including the use of language, that are critical for the child.

6.6 Summary and discussion of chapter six

In this chapter, it is apparent that the Babas have afforded children the ability to access and enjoy enabling environments, firstly from creating the nurturing relationships needed for the child's feelings of security and developing self-confidence, and secondly from having the motivation to make changes for these children to get them communicating, moving, playing and exploring, just like any other child. This means that in terms of the child's development the Baba becomes the 'anchor' (Forbes, 2004) who provides the child with the psychological investment which is lacking in institutional care (Save the Children, 2005; Mulheir, 2011; Nelson et al, 2014; Music, 2011)

Findings suggest that the Babas do not only support the sense of belonging within the dyadic relationship of Baba and child, but that they also provide the child's sense of

belonging to a set of wider communities. The Babas challenge perspectives of disability, not only in relation to how children are treated around a range of stigmatising practices, but also through presenting different expectations of the children. It appears, then, that the Babas are changing the expectations of these children on behalf of their communities. Not only do they become part of the community of the Baba programme, but the Babas also negotiate the child's position within the other services that form part of the project, and with the staff. Further, they introduce the child to a more positive identity within the local community beyond the institution and, indeed, Bulgaria.

Participants' explanations of the significant role of Babas in Bulgaria contributes to an understanding of why the Babas appear to take such a pride in their role and their children's progress. It became evident from the interviews with the Babas that they do not take on this role primarily for the small remuneration, but view their role as a source of pleasure and fulfilment for themselves. Like the parents of the disabled children in McLaughlin et al's, study (2016), the Babas reject the 'burden of care' discourse that often accompanies discussion of 'caring for' disabled children for families. Rather, again like the parents in McLaughlin's study (ibid), they appear to take a great pride in their role.

The subtle, 'ordinary' and seemingly small everyday interactions and encounters were noted as significant 'total happenings' (Winnicott, 1964) in transforming the quality of the children's daily lives in the large institution. The findings demonstrate that the children benefit from these routines and are beginning to understand they have an active role within the encounters. The 'normality' of the type of care the Babas are bringing to the children was summed up by one of the volunteers, Bev, when she commented that they are 'just doing the everyday stuff with the kids'. Findings indicate that it is the 'everyday stuff', for example; caring and responsive feeding,

bathing and health care; opportunities to feel attached, loved by, and connected to their Baba and others; being recognised, understood and responded to as a unique individual with their own unique needs; and having opportunities for mobility and exploration within the immediate environment of their 'home' and the surrounding community, which forms the 'alternative model' of caregiving which I have found to be significant for these children.

In building on chapter five, this chapter shows that it is the attuned and sensitive responses from the Baba that have encouraged the attachment, the developing sense of self and more positive identities, which have next allowed the child to explore and be a part of a wider world. Furthermore, in Bronfenbrenner terms the Babas enlivened and strengthened the child's microsystem, thus having a transformative effect on the child's immediate context for development. This is discussed further in chapter seven.

As highlighted in chapter four, the caregiving practices of staff before the baba programme were aligned with and influenced by the attitudes, beliefs and values within Bulgaria's wider macro systems. This may be due to having worked there for many years where practices have become so rooted that they are difficult to change (Stryker, 2012), or it may be that the detached nature of the staff's practice could also be due to their own emotional harm from many years working in the institutional environment whereby they themselves become institutionalised (David, 2003).

Chapter seven provides further discussion and conclusion to the Babas role and its potential to contribute to the de-institutionalisation process in Bulgaria.

Chapter Seven

Without the Babas the children will still be looking at the ceiling

7.1 Introduction

This chapter revisits the initial research questions and provides a conclusion to the key findings of the research project. In addressing the aim of the study, which was to develop a critical understanding the Babas' caregiving role with the children and to consider its potential to contribute towards the wider de-institutionalisation strategy, the findings will be considered in the light of implications for future theory, policy and practice for disabled children in Bulgaria institutions. It also considers the potential for further research.

In response to the first research question, 'what is the harmful impact of institutional care on children?', in chapter four I presented findings to demonstrate how Institution X, and Area A, functioned as a 'totalising' regime with little regard for children's individual needs, thus reinforcing the already segregated existence of the children, and providing (basic) 'care' without nurture. Children's daily lived experiences were characterised by social isolation and anonymity, where their potential to thrive and flourish has been stifled as a result of organisational needs being prioritised. The consequences of this were evident in the participants' reports of how the children presented before they had Babas, which indicated extreme developmental harm and further impairment 'acquired' by institutionalisation (Nelson et al, 2014; USAID, 2013). Using the existing literature and my own (chapter four) findings which set a context for Bulgaria and Institution X, I was then able to interpret and analyse the role of the Baba in relation to the research focus.

In chapters five and six I went on to address the second and third research questions to develop an understanding of the Babas role, ie. 'what does the Baba do?' and, 'what is the significance of their role for the children in this study?'. I presented and


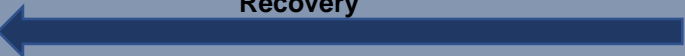
discussed findings which demonstrated that, compared to their previous typical experience of long days confined to their cots in isolated rooms with minimal human interaction, the daily routine with their Baba, over a sustained period of time, provides them with caregiving identified as essential for their survival, nutrition, protection, health and development (WHO, 2004; Bornstein and Putnick, 2012; Lancet, 2016). These caregiving activities would usually be performed by a primary caregiver in a typical family context. Key themes in both chapters five and six highlight the benefits for the children in terms of their overall development, but primarily focus on being able to experience trusting, warm relationships and a sense of 'being' and 'belonging' for the very first time in their lives. Chapters five and six also noted the transformative effect the Babas have on the microsystem.

In chapter five I demonstrated that it is the Babas' positioning of themselves as taking on something of a parenting role which leads to all of these activities and interactions which reflect the domains of parenting noted in chapter two (Bornstien and Putnick, 2012; WHO, 2004; Schofield and Beek, 2005). However, I also highlighted three key components of the Babas' caregiving practices that emerged from the data as significant; 'recognising, noticing and responding'. In using these words I stressed my desire to strip right back to the basics of what is at the core of what is happening for the children in these relationships. I likened this to 'infant care' in 'typical' family contexts in the first instance, but these three features remain significant over time. These key features are not always apparent in institutional care facilities for children, particularly those exhibiting characteristics of the 'total institution', and from the evidence presented in chapter four, 'recognising, noticing and responding' were not central to caregiving practices for disabled children in Institution X before the development of this Baba project.

As an 'alternative' model of care, to recognise a child as a human with rights, to notice what needs to be noticed about the child, and to respond sensitively and appropriately is no different to what most children experience (to varying degrees) in family contexts globally. Surprisingly then, it is a model of care that, despite vast amounts of research over decades highlighting the human rights violations of isolating children in large scale institutions, is not being afforded to many children living in such places and especially children with impairments. Whilst Bulgaria has made progress towards de-institutionalisation targets for 2020 (since the introduction of the DI strategy) (UNICEF, 2014) my findings show that the children in Area A did not experience this model of care until they were given a Baba.

7.2 The Babas' contribution to the De-institutionalisation process in Bulgaria

In chapters 5 and 6 I also noted that the Babas care provides protective factors for the children in Area A. Using Goffman's features of the total institution (1961), which are highlighted as the features of institutional life that cause harm to children, table 5 below captures how the 'actions' of the Babas offer not only a protective factor against the harmful impact of the institution, but in doing so, also play a more forceful role which militates against the institutional regime and its reinforcing practices. Two of the research questions are being addressed here; 'what is the significance of the Babas role?' and 'does the Baba have potential to support the de-institutionalisation of the child while they remain in the institutional environment'? In response to this, the findings demonstrate that three key elements of the transformed microsystem are particularly significant in actively challenging and counteracting the damaging features of the 'total institution'. These elements relate to the promotion of activity, agency and recovery (discussed below). Table 5 (below) provides examples illustrating the forceful nature of the Baba's activities.

Table 5 The 'total' institution 	The Babas' role - resisting the totalising features of Institution X: Activity, Agency, Recovery 
Stigma	Positive attitudes towards the children that work towards minimising stigma. Challenging negative attitudes towards disability and about 'being an orphan.' Presenting the children differently. Actively acting against 'societal othering'.
Physical and Social Isolation Invisible and anonymous	Physically taking children out of their cots, out of their rooms and out of the institution. Taking children into local communities and 'introducing' them to their communities. Children become visible. Holding children 'in mind' when apart and in doing so, introducing them to their own families by talking about their children. Psychologically entering the children into the mind of others outside the institution and in the community.
Batch living/collectively regimented Serves organisational need not individual need	Individualised intimate care routines developed for the children, including feeding, bathing, health needs, play and personalised intimate interactions. Individual daily routines with Baba suited to the needs of the child, not the needs of the institution. Individualised play activities and spontaneous opportunities for walking about the local community.
De personalisation (mortification of self) Rigid routines, lack of individualised care specific to individual needs No personal possessions Anonymous - lacking identity - batch clothing	Taking a pride in the child's overall appearance and presentation; combing hair, selecting 'nice' clothing and encouraging child to do the same. Giving the child a sense of 'belonging' to someone. Encouraging the child to see themselves as a person. They develop as a person with an identity. Using shortened 'pet names' for the children. Understanding their different personalities and encouraging them to develop.
Staff/inmate divide	Acting as the 'regulator' of care for the children which means talking to staff about their children's needs. 'Psychologically' bringing the children closer to the staff.

7.2.1 Becoming a space of activity and agency

As shown in chapter four, the microsystem of the children in Area A before the Baba project was stagnant and inactive. The primary activity taking place was that of the organisational staff as they brought the basic needs to the child who remained in their cots. The 'proximal' processes, which Bronfenbrenner identifies as the key factors in development (Bronfenbrenner and Morris, 1998) and which constitute the 'engines of development' were neither frequent, reciprocal or interactive. In contrast, the children's microsystem since the introduction of the Baba is an active space characterised by emotional warmth and supportive relationships. Furthermore, children's bodies become more active as a result of improvements in their general health, and with support from the Baba, gradually they are able to engage physically with the environment beyond their cot. These explorations in turn enable and support their cognitive and emotional development within a culturally mediated space afforded to them by their Babas who are acting as competent scaffolders of development in all domains (O'Connor and Daly, 2016; Woodhead et al, 1998; Packer, 2017). In Bronfenbrenner's words, the child's world has become a space of 'progressively more complex reciprocal interactions' between the child and the 'persons, objects and symbols in its immediate environment' (Bronfenbrenner and Morris, 1998:996). Of significance in relation to the Babas challenging the regime of the 'total institution' is that the activities are led by the child's needs, not the needs of the institution, and the nature of the daily encounters could therefore now be described as 'doing with' rather than 'done to'.

Whilst Childhood Studies writers claim that children are unlikely to be passive recipients of wider structural processes, I argue that the children in disabling environments like Institution X are so harmed from lack of early investment in their physical and emotional development they have little energy, curiosity, motivation or

even capacity to be a 'social actor'. This relates to 'learned helplessness' (Music, 2011). In these extreme circumstances we do need to acknowledge the vulnerability of these children and offer caregiving which allows for their safe complete 'dependency' on others in the first instance with gradual and progressive, small steps towards increasing independence and agency.

I share the view of Leonard (2016) that to assume children's agency simply because they react in a small way which produces some small change can be misleading, and can reinforce over romantic notions of childhood. Such an approach can neglect the power imbalance in child adult relationships, and ignore the structural differences between adults and children (ibid). Leonard goes on to state that 'childhood researchers adopting a micro analysis often make quite bland statements about the ability of children as decision makers' (Leonard,2016:123) and argues that such purposeful actions are not the same as actions that demonstrate 'agency'. Agency, she argues is an abstract concept, and warns against simplistic interpretations in relation to children.

However, for this thesis, I am interpreting some simple acts of 'choice' and 'resistance' as the *beginnings* of agency for the children. For example, I interpreted Rumen's 'foot stamping' as evidence of his developing agency in chapter six, as this demonstrates a whole new set of behaviours for him which his Baba appears to encourage and facilitate. Agency is therefore understood here in a relational context. Obviously, his Baba has the ultimate power as she can pick him up and place him back into his cot if she chooses to do so. However, she chooses not to, which affords Rumen a level of control and power that he has likely not experienced before having a Baba. Likewise, some of the very simple examples given to me from Babas about their

children's likes and dislikes and how they adapt their own behaviours accordingly, reflect that they are giving the children space to behave in ways that show them they can make some choices, albeit small ones, and within limited timeframes. For children in a 'total institution' like Institution X, this is a positive move towards challenging the perception of the passive and helpless child. For disabled children it is challenging the limiting medically dominated model, thus challenging the stigmatising labels and associated attitudes they have been constrained by since birth. It positions the child as standing out from a 'group identity' allowing them space away from the 'batch rearing' approach which denies them a sense of self. Participants provided very simple examples such as; children choosing what they like to eat, to wear, and which toys they would like to play with which illustrate the child's developing ability to make decisions that influence themselves and others. These opportunities personalised the children and personalised the children's worlds.

Olli et al (2012) argue that for disabled children in institutions their opportunities to develop agency are compromised by a range of factors. These include; professionals who have limiting and/or negative assumptions about disabled children's abilities linked to their impairment (medical model), viewing children's challenges and 'problems' as innate, which means failing to reflect on their own behaviours, and holding views which do not seek to challenge stereotypes and social injustices. In contrast, this study shows that the Babas are clearly contributing promoting factors which facilitate agency (Olli et al, 2012). Their attitudes are more aligned to the social model of disability in that they are challenging stigma and discrimination. In addition, they attribute the children's developmental harm and the caregiving challenges this brings, as more to do with the disabling features of the institution than to any individual pathology of the child, and in their actions they are challenging social injustices both

within and without the Institution. Examples include more subtle actions such as dressing the children differently, taking them outside and 'inviting' others to notice them, and more forceful actions such as changing their feeding practices and, like Baba Margarita, acting as the fiercely protective parent insisting on medication for 'her poorly child'.

Leonard (2016) argues that this would not imply agency in the sense of the children instigating social change. I am however concluding that the Babas' involvement in the children's lives promotes an environment which is more open to supporting the agentic behaviours of children which in turn helps to detach them from their identity as being a child of 'the bloc'. Additionally, the children's histories are acutely disempowered, from the smallest to the biggest choices they have been denied any power. The somewhat small examples show changes in the relationship from one where the caregiver (the institution) has the power, to one where the caregiver (Baba) provides opportunities for choice, which allows the child a perception of power.

As well as the actions and interactions now evident within the child's immediate microsystem, my findings show that there is a climate change of 'recovery' in the environment of Area A and Institution X when the Babas are involved. It is the attitudinal change which forms the back drop to the way the Babas approach their understandings of, and subsequent caregiving practices with, the children.

7.2.2 Becoming a space of recovery and resilience

In chapter two, I discussed the concept of recovery, noting that it can be contentious depending on the context in which it is being used. Recovery, is a concept that in health terms is often used to imply 'getting back to the way you were' (Taylor, 2012:22)

but this is not helpful for use here as the children have not established a positive model of 'who they are' to get back to. In the introduction to the study I noted Rosenberg's comment that to support children who have been institutionalised for such long periods of time in extreme circumstances, it must be recognised that regardless of research showing they will always lag behind in their development, this does not mean that they are 'unsalvageable' (cited in Nelson et al, 2014). The Baba project is working from this starting point. Here, I propose that the Babas' model of caregiving has introduced a culture of 'recovery' in that they introduce some of the internal and external conditions highlighted as the core to 'recovery' in Jacobsen and Greenley's model (cited in Taylor, 2012).

Firstly, the Babas' understandings of, and responses to their children, reflect the internal conditions of 'hope, healing connections and empowerment'. They demonstrate their belief, confidence and hope that the children do have potential to make some developmental progress, recognising the worth of some of the smallest steps. As individuals and as a group they promote a more positive culture around the children, one which challenges the total institution and the limitations of the constant reinforcement of negative stereotypes around both disability and 'being an orphan'. In this sense they are not viewing the child's impairment as something they can 'recover from', rather, they are understanding the 'debilitating effects of early deprivation' (Taylor, 2012:22) as the main reason why their children are showing such extreme developmental harm and offering caregiving which supports 'earned security' (Taylor, 2012:23). This is not to say that the Babas are ignoring the child's impairment but rather avoiding focusing on it as justification for the children's extreme developmental delay in all areas.

Secondly, and 'externally' their input is promoting the external factors in that they are minimising stigma associated with impairment and 'being an orphan' by actively challenging the invisibility and isolation of the child. As noted in the previous section on 'agency', they are challenging the 'societal othering' of the children and minimising both the psychological distance and the physical distance between the children and their communities. Minimising this space between 'them' and 'us' has found to be critical in reducing the risk of abuse of disabled children in institutions (Olli, et al, 2012). In the care that they give, and in speaking up for their children, they transform the microsystem into one which becomes more protective of the child's human rights, and actively promotes their recovery. Such a space of recovery includes,

'Recognising and accepting that there is a problem, committing to change, focusing on strengths rather than on weaknesses or the possibility of failure, looking forward rather than ruminating on the past, celebrating small steps rather than expecting seismic shifts in a short time, reordering priorities, and cultivating optimism' (Jacobson and Greenley, 2001: 482)

This concept of recovery also relates to the development of resilience. Like 'agency', Goodley and Runswick-Cole (2014) highlight the relational aspects of resilience and warn against the dangers of conceptualising it as something that resides within an individual. They suggest that resilience is 'made and remade in relationships with other people and in access to a set of resources' (p.127) including; positive relationships, access to material and physical resources, the ability to exercise power and control especially in relation to one's own body, taking part in a community in a meaningful way which reflects social justice and equality. There were examples of these factors present in the Babas daily encounters with the children as presented in chapters five and six. I am particularly mindful here of Michele's developing independence in relation to her own developing maturity alongside her changing body which the Baba was instrumental in supporting.

It is worth a reminder here that the Baba project involves not only the Babas but a whole team of professionals around the child, including the staff of Institution X, the psychologists, the physiotherapists and the NGO representatives. The quote above from Jacobson and Greenley (2001) captures the underlying beliefs of the organisers developing the project in the first place. However, it is the stable, consistent attuned relationship of the Babas, from which individualised opportunities to discover that the environment can also be a safe place are offered, that is central.

To summarise this section, the Babas have a recovery focused attitude which fosters a space of acknowledging trauma and the impact of this trauma on the children, building on this in ways which promote activity and agency, which can be noted as fostering resilience (Goodley and Runswick-Cole, 2012; Treisman, 2017). All the Baba expressed 'hope' for the child which enabled them to be committed to change and focussed on a 'can do' rather than a 'can't do' attitude for the children. This fits in with the challenges often levelled at Goffman's work (Goble, 2008). His work is critiqued for assuming that the 'inmates' are at the receiving end of the institutional features, whereas other writers have proposed that 'inmates' use a range of strategies to resist these totalising forces. In this study, the Babas are resisting the totalising forces on behalf of the children.

In transforming the microsystem the Baba is creating resilience around the child which may lead to better outcomes. For example, adding to the children's growing repertoire of self care skills and self efficacy could potentially support them in their own deinstitutionalisation whilst remaining in the institution and beyond, making that child more adoptable, or better equipped to fend for themselves if the next stage for them is another form of institutionalisation (including small group homes). This more active role supports the realisation of the children's rights, the child's developing identity as

an agentic person, the child's identity as a person with a sense of belonging to a wider community, and resists negative attitudes around disability, impairment, and 'being an orphan', which have been the primary signifiers of identity for these children since birth.

I conclude that the Babas offer a strong force in counteracting the features of Goffman's 'total institution' and in doing so, they are facilitating the 'de-institutionalisation' of the child while the child is still in the institution (as highlighted by a selection of examples offered in table 5). This has a significance for the child as 'being', in that they are now recognised as a human being, a child worthy of being valued and validated by others, and a child worthy of human rights. They are also 'being', in the context of meaning no longer caught up in that "betwixt and between" position of liminality (Turner, 1969:95). This will now be addressed in relation to implications for policy and practice.

7.3 Considerations and implications for future policy and practice

Having established the role of the Babas and identified that they are playing a part in the de-institutionalisation of the child while they remain in the institution, the following section considers this in relation implications for policy and practice, thus responding to the final research question; 'what are the implications for policy and practice?'

7.3.1 Supporting Transitions

Disabled people in post socialist countries, including the children in Institution X live in a societal context of 'weak safety nets, unstable politics and ambivalent civil society development that make it difficult to overcome historical legacies of control, segregation and stigma' (Rasell and Smirnova, 2014:1). The transitional policy context

has been recognised as a key risk factor for children in institutions (Brooker, 2008; Fabian and Dunlop, 2006).

In the introduction to this thesis I expressed my concerns (during my early volunteering visits when de-institutionalisation process was in its earliest stages) that children in Institution X were caught in the gap between the policy development and its implementation. Mitchell (2005) refers to the 'human cost' of the gaps between policy and practice. The human cost for the children in Institution X has been established in chapter four in terms of the daily lived experiences of the children and the harmful impact of this on their development. This is compounded by the fact that the de-institutionalisation process is a long drawn out and complicated process of transition, made even more complicated because the country itself is in a critical period of economic transition, as well as being in a process of navigating the cultural and ideological shifts tied up in their relatively new EU identity (Stryker, 2012). Transitions are not a 'one point' event (Vogler, 2008:10). Change does not happen overnight and periods of transition are notoriously difficult, especially so for children in such vulnerable conditions as those in Institution X. For the children in Institution X, some of them who have lived there for over 10 years, the human cost is already very evident. Bearing in mind the extent of developmental harm for children exposed to harsh institutional conditions, and evidence suggesting that harm is greater as a result of longer periods of institutionalisation, time is precious. It is therefore vital to begin a form of 'de- institutionalisation' during the policy/practice transition phase.

Using the explanation of 'transition' offered by Vogler (2008), the intended physical (geographical) de-institutionalisation for these children to other places is a transition in which the child needs to negotiate the vast changes ahead, specifically in relation to 'activity, roles and relationships, as well as associated changes in use of physical

and social space' (Vogler, 2008:1). What the findings of this study demonstrate, is that the Baba, working with the child *in* Institution X during the 'waiting period' is introducing an 'intermediate transition' for the child which also involves every aspect of Vogler's definition. During this intermediate transition, the child is being supported through changes in their appearance, activity, status, roles and relationships, as well as associated changes in use of physical and social space, and/or changing contact with cultural beliefs, discourses and practices...' (Vogler, 2008:1). In a sense the Babas are 'priming' the child by supporting their development ready for their next stage of de-institutionalisation.

The transition taking place within the institution with the Baba is therefore the transition from an institutionalised routine to a more individualised routine, and from an institutional identity to an individual identity. In doing so, the child's identity and status changes both within the institution and outside, in their community. This may appear to amount to seemingly small changes, for example, a child who has never been seen in the community is now 'sometimes' visible, but it is a significant change nonetheless. This represents an intermediate transition from 'institutionalised' to 'de-institutionalised' in relation to all of the aspects of Goffman's total institution.

Like de-institutionalisation, changes in attitudes take a long time and take place as a result of a complex range of influences, many occurring in the macro systems. Walker (2011) proposes that de-institutionalisation can only happen 'hand in hand' with attitudinal change. The Babas' activities with the children are making a contribution towards the transitional process of attitudinal changes in their local communities and are therefore supporting the policy and practice context of de-institutionalisation.

7.3.2 Effective Intervention supporting De-institutionalisation

Bronfenbrenner (1992) and Myers (1992) suggest that the most successful and powerful interventions with children are those that have at their core opportunities to build up a supportive ecology around the child. To do this, they should be built around the customs and values of the communities in which children have their roots and should be meaningful to their communities. In General Comment 7, the UN Committee on the Rights of the Child reflected this awareness of culturally diverse child-rearing goals and practices and encouraged those working with young children to “draw on beliefs and knowledge about early childhood in ways that are appropriate to local circumstances and changing practices, and respect traditional values” (Vogler, 2008;14).

It is also recognised good practice for interventions that promote children’s development to reflect multi disciplinary perspectives (thus reflecting the multi facted nature of child development) and should be community based with community involvement (Bronfenbrenner, 1992; Myers, 1992). Bronfenbrenner (ibid) pointed out one principle that pervades all others - a primary focus on strengths, which has already been noted as a key aspect of the Babas’ role. In addition, the findings reflect Bronfenbrenner’s proposition that families need supportive layers. In this case, the alternative family form of each Baba and ‘their’ children, benefitted from the input of the other Babas and professionals around them. They formed a protective factor around the child that reflected a supportive wider ‘family’ network.

The Baba programme, due to its key feature of employing local older women, is remaining very much at the heart of the community around the institution whereby older women are being included in child rearing practices and revered for their

'traditional wisdom' (Myers, 1992). The participants in this study provided me with examples of how the Baba is a much loved and well-respected member of the Bulgarian family and is traditionally associated with caring for the children. In relation to building up supportive ecologies around the child, the Baba is paid a small wage which not only boosts her own income but due to the interrelated nature of the systems around the child (Tudge et al, 2009), will also have a knock on effect on the local economy. All of the Babas commented that their involvement in the programme supported their own emotional well-being by giving them a sense of purpose and supported them in remaining active, again highlighting potential gains for the local economy in terms of the well-being of the ageing population. In terms of being meaningful to local communities, the Baba programme made sense to the participants in this study on the grounds that meaningful relationships were being established between two lonely and isolated groups; the institutionalised children who are stigmatised and marginalised due to social factors such as disability and poverty, and the retired, older women who commented that their families are often leaving the local communities to seek employment opportunities elsewhere, taking their grandchildren with them.

Furthermore, it is not only the children who live in the Bulgarian context of an unstable and weak safety net. The transitional economy has also had an impact on the lives of the older women in the Bulgarian communities. In chapter two I noted that Bulgarian pensioners are one of the poorest groups and vulnerable to further poverty (EU Publications, 2015). The Baba project provides a means by which the Babas can contribute to their family income, thus maintaining independence and a better standard of living for themselves. However, I must emphasise that this is *my* interpretation as most of the Babas commented that the money is not their primary

motivation for being involved with the children. In contrast to prioritising monetary gains, the Babas focused on the pleasurable aspects of the role, and the new personal connections they are experiencing as highlights of the role for them.

Intervention programmes are most effective when they include caregiving practices which challenge discrimination and social injustice (USAID, 2013). The Babas in this study offer caregiving which is based on getting to know the child and developing expectations for the child based on what the Babas themselves have 'noticed' about their child. The Babas come to the relationship with the child with open minds as noted in chapters five and six. They have been told what to expect from their child by the staff of the institution, for example, 'he will never walk', but they develop their own expectations built on getting to know their child. At a micro level, the Babas themselves are presenting different models, or 'ways of seeing' the children in Institution X. They appear to be challenging the discrimination and social injustices that go hand in hand with impairment, and 'being an orphan', and by taking children into the communities and 'showing the children to their nation' (Emil, NGO) and vice versa, attitudes can be changed locally.

One of the key challenges facing Bulgaria in developing small group home facilities is to maintain low numbers of children in each home to avoid 're-institutionalisation' (Ivanova and Blogdanov, 2013; Sinson, 1994). In 2011, authorities proposed group homes with up to 15 children which, with small numbers of staff in each home, could still recreate the characteristics of a 'total institution' (Ivanova and Blogdanov, 2013). This fear was echoed by the Babas themselves, when I asked them how they would influence policy if the policy makers would listen to their views. All of the Babas said they would not take the children from InstitutionX but requested continued support with the Baba project within the large institution. I believe this was not out of a lack of

knowledge about the harmful impact of institutional care, rather out of a deep and real concern that children may become even more invisible out there in 'small' group homes. At the time of this study I was aware that the Babas had heard that one of 'their' children had been attacked in a small group home by an adult male who was sharing the home with her. The girl was 9 years old. It is not surprising then that these stories cause concern for the Babas and might therefore position the large Institution as a safer place for the child.

On this note, one critique that could be aimed at the baba project as an intervention, is that they are part of a project which has also involved the refurbishment of parts of the large institution in the areas used by the Babas. The Baba project could therefore be viewed as reinforcing the continued institutionalisation of children by enhancing the living conditions within the institution. This particular Baba programme, like others across Bulgaria, is overseen by an NGO which receives much of its funding from international donors. USAID (2013) reports that humanitarian and seemingly well-intentioned work with children has negative consequences as when positive changes are reported and seen in local communities it can lead to the misconception that the state can provide effectively for the children. Even simple changes like introducing the children in Institution X to a better diet and having a play room and designated areas for physiotherapy and massage, can reinforce that state care in large institutions is acceptable, which can undermine the de-institutionalisation process.

However, a report by the Open Society Foundation (2012) argues that there are some limited circumstances where funds can be used to improve the environment; firstly, where conditions are identified as life threatening to the residents and immediate action is necessary to address this, and secondly, where they are used to house

activities that from part of the wider strategic de-institutionalisation targets towards community based services for children and families. The Baba programme could be viewed as meeting both criteria.

This is critical because findings from the perspectives of my participants lean strongly towards the significance of the Baba as an 'outsider' to the organisational culture of the institution. They are a new person coming in with fresh eyes, yet steeped in 'old' culture, traditions and experience of caring for children in family and community contexts. This suggests that programmes like this one need to remain within the organisation of the NGOs rather than becoming part of the state response to child protection concerns. The Baba acts as a mediator between the child and the staff, and the child and the community. If they were to become a member of paid staff in the large institution or small group home, they become part of the institutional culture that they are in place to counteract, thus defeating the object of their role. The lead psychologist (Todor) expressed this strongly, saying that the Babas need to be 'recognised as something coming from outside of the institution...the program is very efficient and beneficial but everyone has to be careful on the way they are using it. If this program becomes an official strategy it will no longer function the same way'.

In conclusion to the overall research aim of exploring the Baba project's contribution to the de-institutionalisation of disabled children in Bulgaria, the Baba project reflects a simple, alternative model of caregiving for the children in Area A of Institution X. It allows for cultural specificities and reinforces the interrelated nature of the micro, macro and chronosystems. It is a model which challenges traditional views of the passive child as 'receiver' of care and development, which also challenges passive and pathological disability identities which are typically ascribed to disabled children.

It is a model of caregiving which is a 'good fit' in transitional periods of de-institutionalisation as it focuses on the ones who are 'left behind' in the liminal space therefore being child centred. Such a focused effort to 'de-institutionalise' the children whilst they are in this stagnant period of waiting, creates changes in the child's microsystem, minimises risk of further harm and introduces protective, 'healing' factors. The Babas provide an intermediate safe space of activity, agency and recovery which counteracts the characteristics of the 'total institution' and promotes resilience.

Overwhelmingly, the key finding is that the Babas provide the one feature most lacking in institutional care regimes for children, the absence of which is deemed as the most damaging aspect of institutional care, and the presence of which is identified as the most protective factor, that is, the emotional investment from a loving caregiver. The Babas have been identified from these findings as providing the 'enduring relationship' that provides the protective factors for these children (Jack, 2000). It is the sense of 'belonging' to their baba, and the Babas' sense of their child 'belonging' to them, that is core to the healing nature of the relationship. By taking the child out of the institution both physically, and psychologically, the child is becoming visible again as a human. This increasing visibility can be a small step towards the long journey ahead for attitudinal change towards disabled children in Bulgaria.

The Baba project is by no means the answer to a whole host of highly complex and intricate reasons which underpin the high rates of institutionalised children in Bulgaria, and which also operate as barriers to the success of de-institutionalisation. Neither can it stand alone from a whole strategic process of de-institutionalisation which involves an overhaul of the system of child protection, the development of a range of services to support families to avoid the need for institutional care, workforce

development and massive shifts in attitudes. However, I conclude from the findings of this research project, that whilst it is not ‘the answer’ in ensuring the best outcomes for disabled children, during the de-institutionalisation period it is a positive intervention which is founded within the heart of the local communities around the institutions and can be positioned as a small, but effective, part of a much larger set of responses and targets.

7.4 Reflecting on the research decisions

During the period of this PhD research, from the beginning to the writing of the conclusion, I have maintained a reflexive stance which has instigated many peaks and troughs along the research journey. In keeping with the reflexive tone of the thesis I now provide an honest account of what I perceive to be the strengths and limitations of this PhD research, including my reflections on my own conclusions.

7.4.1 Original contribution to knowledge

In sections 7.2 and 7.3 of this chapter I presented conclusions from the findings of the study which overwhelmingly identify positive aspects of the Babas’ involvement with the children in Institution X. In identifying the strengths of this project I still have the absolute conviction that I had at the beginning of the study, that this is an area worthy of study, and an area which needs further research from a range of perspectives. The subject of children’s daily experiences of caregiving within alternative arrangements to family care is of increasing interest in academic, policy and lay circles growing internationally. The subject of children’s development is fascinating and when examined alongside additional layers of historical, social, economic, political and cultural factors, it becomes even more so. The history of Bulgaria and the influence

of the Soviet ideology of the past has added a dimension that I believe is worthy of further consideration, especially to address issues that can arise when de institutionalisation programmes are influenced by a global, rather than local agendas.

In terms of research, as noted by Stryker (2012), former communist countries rejected much of the child development research around emotional development and attachment as it was not compatible with their perspectives of childhood of the time. Similarly, Disability Studies models developed in different countries have grown from their own particular histories and cannot easily be 'imposed' elsewhere (Armstrong and Barton, 1999). Research and scholarly activity into disability in Eastern Europe and the former Soviet Union has been 'patchily covered' largely due to the area's lack of engagement with the global research community (Rasell and Smirnokova, 2014). This 'scientific isolation' (Nelson et al, 2014) not only impacted on children's experiences in institutions but has impacted on research in this area. Studies that have been carried out in Eastern European countries have relied heavily on the analysis of documents due to restricted access (Rasell and Smirnokova, 2014).

I am therefore very privileged to have been able to gain access to the participants for this study, and I feel this has enabled me to gather rich data from an otherwise 'closed off' research field. Likewise, a report by USAID (2011:1) about early child development intervention states that 'there is virtually no research on ECD interventions designed specifically for orphans and vulnerable children'. This access to an otherwise restricted research field has allowed me to contribute to understanding the daily lived experiences of disabled children in a Bulgarian institution, which includes the voices of their primary caregivers. It also adds to the sparse body of

research on the development of 'orphans and vulnerable children'. This therefore forms part of my original contribution to new knowledge in this area.

The conceptual paradigms of Early Child Development (including developmental psychology), Childhood Studies and Disability Studies used, offered a fusion of lenses which I was able to draw together in a complimentary way, to develop a deep and critical understanding of the children's experiences and the significance of the Babas' caregiving practices. I engaged with both the wider influences on the child which have led to distinct constructions of childhood and disability in Bulgaria, and I also paid attention to the micro world, drawing from perspectives on early childhood development to understand the children's daily experiences. The intersectionality of the disabled child has been made visible by using different approaches. Such an eclectic mix of genres helped to move beyond trying to analyse a complex set of circumstances from a one-dimensional perspectives to something that was more useful given the very unique ecosystem of the children in this study. As highlighted by Walker (2011) one theoretical position is not enough to understand such complex situations. This fusion of lenses has also added another dimension to my original contribution to knowledge in the area of disabled children's experiences of institutionalisation.

7.4.2 Reflecting on theoretical and conceptual positions used.

As stressed from the beginning, this research primarily sits within a 'Childhood Studies' genre as it has at its core the study of children's lives, taking an interdisciplinary approach and acknowledging the complexity of their experiences (Smith and Greene, 2014). I began the study in 2010 during which time I was more embedded professionally in child development literature especially around

attachment, the emotional needs of young children and caregiving practices. My own preferred approach to the study of children's development lies very much in the ecological and socio-cultural models (Bronfenbrenner, 1979; Bronfenbrenner, 1986; Super and Harkness 1986; Rogoff, 1990) which align well with key Childhood Studies principles emphasising the socially constructed nature of children's lives and which recognise that children are active agents in the construction and determination of their own lives (Wyse, 2003). I was, at the time of starting the study, troubled by the 'wall of silence' that existed between the 'Childhood Studies' and 'Child Development' camps and the binary opposition this both created and reinforced (Smith and Greene, 2014). I was mindful of this as a potential barrier to analysing the experiences of the children in institution X and I worked to create an analysis which included consideration of both agency and structure and emphasises the relational nature between the two.

In addition to negotiating tensions within the disciplines of Child Development and Childhood Studies, I found that as the study developed I became more engaged with some of the arguments from Disability Studies. As with Childhood Studies and Child Development, there is the added dilemma that there are many positions within Disability Studies, with each potentially offering a different interpretation (Cameron, 2016; Shakespeare, 2014). In terms of the disability literature, I stated early in the study that I was drawing from the Social Model of Disability (Cameron, 2016; Barnes et al, 1999) which also aligned with the ecological approach to children's development (Bronfenbrenner, 1979). I used the literature to understand some of the material, structural and cultural conditions which led to the marginalisation of disabled children in Bulgaria in the first place and which reinforced the continuation of these harmful practices. These social model perspectives were useful, and compatible with the

ecological approach to child development, particularly in the analysis and presentation of the data in chapter four.

As the findings emerged, especially when I began to focus on the role of the Baba in meeting the intimate care needs of the child, I became mindful that I was describing and understanding the embodied experiences of the child and the role of the Baba in this. Children's geographers (Stephens et al, 2015) and disability writers (McLaughlin et al, 2008) have commented on the significance of the embodied experience to support children's understanding of space and place, and to support their understanding of their own bodies and their developing sense of self in relation to their bodies and the bodies of others. For the disabled children in this study their bodies are excluded from society because of their impairments, their bodies are the site of a range of 'done to' harmful practices, and with the introduction of the Babas the children are experiencing their own bodies differently for the first time. I re-read my findings and found that I and the participants had referred to the child's body on many occasions.

In reflecting on my literature review and how this has informed my analysis, I view my lack of consideration of 'embodiment' as a gap worthy of reflecting upon here, and one which offers opportunities for much deeper analysis and discussion than can be dealt with at this stage in the PhD. As highlighted by Stephens et al (2015:195), 'lack of attention to specific bodies and particular experiences can result in a disembodied approach'. Disability Studies writers are now challenging the social model focus on disabling barriers 'out there', whilst also remaining cognisant of the need to avoid pathological medical model discourses. Shakespeare (2014:75) for example, taking a critical realist perspective proposes a more holistic interactional model, and

suggests that ‘people are disabled by society *and* their bodies’. Other critical disability writers present studies about disabled children which do address concepts of embodiment, and other previously ‘uncomfortable’ concepts in Disability Studies, such as ‘care practices’ (McLaughlin et al, 2008; Davis, 2012). The concept of ‘care’ has always been problematic to Disability Studies as it implies perceptions of the disabled person as helpless, dependent and in need of ‘care’ (Cameron, 2016). However, analyses of disabled children’s experiences as ‘embodied’ allows for the inclusion of caregiving and relationships as these are critical in facilitating the child’s exploration and understanding of people, objects and environments in all domains of development. Some Disability Studies writers also acknowledge that the body can be a place of pain and discomfort, and that there is a valid place for consideration of the concept of vulnerability and intimate care in relation to disability (Kittay, 2002). In relation to this PhD study, it is recognised that children without parental care and especially disabled children, are very vulnerable to institutional caregiving practices.

Identification of this ‘gap’ around embodiment, also highlights some of the other conceptual tensions I experienced especially during the interpretation of my data and presentation of findings. There were times when I would have liked to interrogate my findings differently using a more prominent Disability Studies lens, but I was also mindful of getting caught up in distraction from the primary lens of children’s development which was the original focus. To illustrate this briefly as a final reflection on the theoretical perspectives and literature used, I am using the example of Michele. In chapter six I presented Michele’s ‘new’ identity as a girl, and her Baba’s role in supporting this, as a positive step for Michele. For an isolated and ‘invisible’ child like Michele, this gender identity can be viewed as a step towards becoming a ‘someone’ and could potentially make Michele more adoptable, thus enhancing Michele’s

chances of belonging to a family rather than the state. Within the context of the other findings around identity (also presented in chapter six) this positive interpretation seemed appropriate even though it jarred with my own views around constructions of gender and societal responses to this.

From a Disability Studies perspective (which reflects my own position on this particular issue), operating on Michele's body implies medical model perspectives which view Michele's body as a 'tragedy' to be cured. Or, in the words of Sherri Morris in her personal account of similar treatment, 'a tragic mistake of nature' (Morris, 2006:4). It is highly undesirable to perform such risky and painful surgical procedures on children in order to 'normalise' their appearance (Parens, 2006; Shakespeare, 2014). From both Childhood Studies and Disability Studies perspectives there are ongoing concerns that children should have an active participation in making decisions about whether to have such operations that they might regret later in life. There are also ongoing discussions about the role of parents in this decision making process (ibid) which raises further questions about the nature of the process when the 'parent' is 'the state'. This one example highlights the complex interplay of embodiment, impairment and caregiving and also exposes some of the tensions inherent when attempting to understand from a range of various perspectives and genres.

These tensions are not unavoidable and on a positive note, provide further opportunities for reflecting upon one's own epistemological and philosophical assumptions. This stance reflects current motivation in the area of Childhood Studies and Disability Studies to continue to progress work with both positions to create fuller understandings of disabled children's daily lived experiences (including embodied

experiences) as well as taking into consideration the wider structural arrangements around the child and family (McLaughlin, et al 2008; Connors and Stalker, 2006).

7.4.3 Reflecting on the research design

From the beginning I have had ongoing concerns about the limitations of carrying out research in another country with a very different cultural history to my own country of birth. Those concerns do still sit with me, but coming to the end of the research project I now believe that this can also be positioned as a strength. Having come to the study with little understanding of Bulgarian culture, I was able to notice aspects that Bulgarian people might have taken for granted, for example the celebration of Martenista, or the celebration of the 'first steps' of the child. This outsider position led me at times, to delve more deeply into the meaning of some of the activities and interactions between the Babas. It has also led me to reflect on my own culturally embedded notions and understandings of children's development which have come from the personal and academic experiences of belonging to a UK context.

In terms of the research design, I am conscious that certain children have been highlighted more than others in this study. I therefore consider that a case study approach whereby I focused on one or two children in more depth might have added to the study. However, this would have involved a full ethnographic approach which would have been difficult given the travelling issues and the timescale available. I paid full attention to 'watching my writings' (Goodley and Runswick- Cole, 2015) as I was committed to achieving the balance of highlighting the 'tragedy' of children with impairments being placed in institutions from birth and experiencing the extremely harmful impact of this, including early death, whilst also presenting the children of this study as unique individuals with their own developing personalities in a positive way.

I have therefore tried not to present the children as passive and tragic victims and I have also importantly, tried to avoid presenting the Babas as 'heroic self-sacrificing 'savers' (McLaughlin, 2016). At times during the findings some of the participants' descriptions of the children, including the volunteer poems, could be seen to be presenting the children as 'tragedy', however, within the context of the interviews my understanding was that these views reflected the volunteers' emotional responses to seeing the 'tragedy' of institutionalisation of children with impairments, and not the 'tragedy' of disability.

In chapter three, I contemplated issues of voice and for me it will always be a limitation of my study that I did not capture the voice of the child. However, in my interpretation of the findings I was mindful of presenting the authentic voice of the participants, particularly the Babas in recognition that they are the nearest voice to the child that I would get. Also relating to 'voice' there are limitations with regards to my findings overall. In part this is due to my reliance in the interview on the voice of the lead psychologist, Todor, and the NGO representatives, all of whom could be perceived as having a vested interest in the continuation of the Baba programme. Of course, the Babas themselves also have a different kind of interest in maintaining the programme.

An alternative voice might have included stronger critiques of the programme. Organisations like LUMOS for example, are strongly against any work that appears to be maintaining the use of large institutions. They present critiques of 'voluntourism' and international donations that continue to work within institutions, thus reinforcing this practice of alternative care and often providing financial incentives for 'orphanages' to be run as business opportunities. The political and economic impact of 'voluntourism' may be the continuation of inappropriate institutional contexts

despite the international drivers that are trying to move away from them. The NGO voices presented in this study also work with charities that support volunteering projects in 'orphanages' and could therefore be considered to be promoting their own interests. Projects like the baba project, funded largely by international donors and managed by NGOs could also fail to acknowledge the risks and barriers to successful de-institutionalisation of disabled children (Terziev and Arabska, 2016) and therefore inadvertently support the practice of institutionalisation.

I do acknowledge these potential limitations around voice and the resulting findings and conclusions, but I do maintain that the voices I sought were appropriate in order to respond to the research questions, in this case to gain a deeper understanding of the Babas role with the children. In seeking the opinion of the lead psychologist in relation to some of the design issues, and in presenting his voice as a strong presence throughout the study, I was trying to navigate the tensions of being an 'outsider' doing research in a context outside of my native country. In seeking and presenting the voices of the NGO representatives, my own interpretations were that they appeared to be child centred and focused on the needs of the children. Like the reflections around conceptual limitations (in 7.4.2), this is an area where much further discussion is necessary and cannot be fully explored within the confines of this thesis.

7.5 Revisiting Bulgaria and reflections on my conclusions

As I approached the submission date of this thesis I arranged to revisit Bulgaria with the main intention to revisit Institution X and some other institutions, to discuss my key findings and conclusions with stakeholders and to ponder my own personal reflections about the de-institutionalisation of children in Bulgaria. It was too late in the day to make any significant changes to my findings but I was still keen to discuss

them with interested parties who had been involved in my study from the beginning. I arranged the trip for March 2018. I was meeting with one of the NGO representatives I knew, and was also meeting socially with Bulgarian friends I have made over the years. Coincidentally, the timing coincided with the Martenista customs and celebrations that I had witnessed and written about in my very first visit exactly 8 years previously.

During the week of March 2018, some reflections from two of the visits to institutions are relevant to the findings presented in this thesis, and I feel worthy of sharing to support the conclusions to this research. These additions are not intended to be read as additional data, rather they are included as additional reflections on the research project and to 'round up' my ongoing focus on reflexivity, as well as highlighting further potential research areas. This also indicates that this is an ongoing area of interest and commitment for me, for me which I intend to continue with in my 'life after PhD'.

Visit One- I arranged to revisit Institution X which I had last visited in 2016 when I had returned to Bulgaria to carry out some interviews during the data collection phase of my study. Chapter four reflects some of my own experiences of the characteristics of Institution X in March 2010 and when I completed periods of volunteering over the next 3 years. On the journey to Institution X, a friend and I were talking about our previous visit when we had met the new director who had instigated many positive changes including more personalised caregiving practices and the continuation of the Baba programme. We discussed an incident during the 2016 visit and reflected upon it in relation to my findings. We had bumped into one of the Babas who I interviewed for this project. She remembered me and we greeted each other with a hug. With tears in her eyes she told us that her child 'Michele' had been adopted to America and

that she missed her terribly. She said 'I loved her like she was my own' She took out her purse to show us a picture of Michele. She removed the photo and looked at it herself before showing it to us, she then smiled and held it to her heart before putting it carefully back inside her purse. This reinforced for me the conclusion that the Baba needs to be a significant other, like a 'real' family member, and not a member of paid staff at the organisation. This expectation of the role to be like a 'normal Baba' is not one that can come with an organisational job description as that would require the denial of attachment and love in the relationship.

When I entered 'Room A' the immediate observation was that the smell had gone. Generally, the children looked much better cared for, their bodies were clean, their bedding was fresh and they seemed bigger. I noticed that all of the children were wearing Martinista bracelets this time. In 2010 I had noted in my diary entry that only some of the children were wearing them. This signified this time that all of the children had been included in this important Bulgarian celebration. From one of the rooms I could see through a glass partition into another room where one of the care staff was feeding a child. The child was lifted out of the cot and was being fed on the carers knee, being held appropriately. It looked like the carer was talking to the child. My friend was drawn towards a small child who was sitting up in his cot smiling across at her inviting attention. She played with him over the cot for a few minutes and then we said goodbye. We were both surprised when he started to cry, calling to us in Bulgarian, 'no good bye, no goodbye'. We were both upset by this and we asked the psychologist showing us around to explain to the child (in Bulgarian) that their Baba would come soon. Afterwards, we reflected together that the reason it upset us was that it had never happened before. In Area A, we had never seen a child talking, let alone expressing their need not to be left alone. I felt so sad about the child crying 'no

goodbye’ but afterwards I reconfigured this as a potentially positive observation. It implied that the child was used to having visitors to their room, and most likely a Baba. The child was able to express himself and he was also able to settle when the psychologist explained that the Baba would come soon, suggesting that he understood the routine. For me, despite my initial concerns, this signalled positive changes in Institution X.

One of the key changes that I would confidently attribute this to was the appointment of a new Director. It was evident she had changed practice and that her own commitment to the children had filtered down to the staff. She spoke of children who had been adopted who she had continued to receive updates about. She spoke about the children with a genuine warmth, and her own young daughter was often in the institution visiting the children. I reflected upon this in relation to ‘evil individuals’ (Goodley and Runswick- Cole, 2011) and how, whilst acknowledging that there are high rates of abuse in institutions (Mulheir, 2012), it is critical to avoid falling into the trap of demonising caregivers for reinforcing harmful practices. On the day of the visit to Institution X, I saw a young man with a range of complex impairments, who has spent his whole life in Area A since birth. He spends his days lying on his back and rarely leaves his cot. I noticed he looked much healthier and happier than in previous visits, and he had put on lots of weight. The psychologist told me that he was supposed to be leaving Institution X as he had reached the age of ‘moving on’ to adult facilities. The care staff in Institution X had put their own money together (despite their minimum wage), to maintain his stay with them as they were concerned about him moving on. Such positive stories are worthy of inclusion in works like this.

Visit Two - This was to an orphanage that I hadn't been to before. It had been a large institution with over 100 children but not as large as Institution X. The Bulgarian contact who had arranged the visit wanted to show me a Baba programme that had been established in the orphanage for the (non-disabled) children, and as it was International women's day the children had been working on a celebration event with their Babas that she was keen for us to attend. We drove for over an hour from our apartment to get to the institution, along roads that became more winding and narrow as we seemed to get further and further away from the city. Eventually, having driven through the hills, I saw what appeared to be a very small town ahead with derelict buildings scattered around it. As we drove into the main area of the town my first impression was that of a 'ghost town'.

The main street seemed to have a small selection of run down shops and a very small garage, at the end of which was a community centre where the 'event' was to be held. However, due to a slight hold up in the timings, the Director of the institution suggested that we drive along to the institution to see the refurbishments (this was to give the Babas and children more time to prepare for our arrival). The NGO representative explained that the Institution, funded the NGO (from their international donations) had recently refurbished an old barn to make it into day centre for children with mild learning difficulties and physical impairments from the local area, and that their families were being encouraged to support their attendance. As we pulled up, I noticed that all of the children were being ushered out of the building by some of the carers. We were directed into the day care centre, a very small space which was now used to provide activities for approximately 12 children and young people with physical impairments and learning difficulties. The 'rehabilitation room' which was also very small, had a set of obviously brand new equipment which appeared unused. The walls

of the room were bare. The small 'play room' had a TV and some seating around the sides. The shelving on one wall contained mainly soft toys of little educational value which again appeared to be positioned for aesthetic value.

After our brief tour of the small day care centre, we asked if we could visit the orphanage which was in the same grounds. Even though the children from the orphanage were busy preparing for us in the community centre up the road, the Director wanted to show us the changes she had made to attempt to 'de-institutionalise' the large institution. To get to the orphanage we walked through the garden past the children from the day care centre who had been gathered into a setback seating area presumably so as not to bother us. I was told by the NGO representative that all of the children were from the Roma community living locally in the town. I reflected upon the intersectional nature of institutionalisation of children in Bulgaria, as most of the institutional population are from Roma families. Whilst attitude change is still needed towards disability, there are huge shifts of attitudes still required around Roma communities. This was an aspect that I had not investigated in my study and an area I feel is worthy of attention.

In the orphanage we were shown the 'transitional' corridor which was a set of rooms that had been sectioned off and refurbished to make into small flats for groups of young people who were almost ready to leave the institution. The young people were sitting in rows in the main corridor when we arrived and we were taken to see their 'private' rooms.. I was shown into the shared 'apartment' of 3 young women which had one room with settees and a tv, and another room had beds with a small table next to each bed. I was trying to talk to the young women using the interpreter and I was praising them on how tidy their room was, and asking if they had been busy. The

young women, aged between 15 and 17 seemed very immature. There was nothing on the walls of their rooms to suggest any individuality or personal interests. There were no personal items scattered around the room. The rooms off the corridors were also used for groups of young men, and the two staff on that particular area at the time were both male. I was aware that I felt very uncomfortable about this.

On the long drive back to Sofia I saw three different young women at the sides of the road trying to flag down cars. The NGO representative told me that many of the young men and women are vulnerable to sexual exploitation as they get older both within the institution and when they leave. He also told me that de-institutionalisation in Bulgaria is a 'fairy tale' pointing out that when the children go to small group homes they become lost, and do not access the range of services because they do not really exist. This made me wonder about the Babas' own views that the large institutions should remain in place with improved services - perhaps my interpretation that they have local knowledge of de-institutionalisation not working is justified. Later that evening, I couldn't help but think about the three young women I had just met that afternoon and I wondered what kind of project might support their transition from institutional care into the community. I reflected upon the needs of young people leaving institutional care and the need for protective factors. This led me to wonder whether a Baba programme could effectively support older children and young people. I also wondered about the potential of 'grandfathers' also being involved in future projects (I am pursuing this line of thinking with Bulgarian NGO colleagues).

We arrived at the community centre to be greeted by a Baba and two young girls aged around 13. They welcomed us with warm bread with spices (a Bulgarian tradition) and directed us into the community centre hall. The hall was set out with approximately

eight tables around which Babas and children were gathered with craft activities in front of them. The atmosphere was very warm and welcoming and both the children and Babas seemed excited to have visitors. Over the next hour or so we were treated to a range of performances including small groups of children singing, offerings of Mother's Day cards and paintings and readings from Mother's Day cards. During these times the Babas were encouraging the children to take part with confidence, and small gestures such as approving and encouraging smiles, gentle pushes in the right direction and stroking of children's backs while they were working.

The highlight for me was when the children excitedly encouraged the Babas to sing a traditional Bulgarian song. While the Babas were singing I noticed the children were smiling at them affectionately, some children holding their Babas' hands and others stroking them while they sang. It was as if the children were offering the same kind of encouragement to their Babas that they had received from their Babas. It seemed ironic, and I felt sad that these children were writing and singing about the celebration of mothers, however, in the spirit of international women's day it seemed meaningful that the Babas were involved in such celebrations. At the end of the celebrations the children were taken back to the orphanage and the Babas started their own separate celebrations with homemade Bulgarian food and wine. They were gathered around a large table together, approximately 15 of them, smiling, chatting, laughing and singing, and I thought to myself it was wonderful to see these older women gathered together in this little community centre in what I perceived to be like a ghost town.

I reflected afterwards that I had experienced some annoyance about the ushering of the disabled children out of the activity centre upon our arrival, and the lack of 'personal' items in the rooms of the young women in the transitional corridor. I

considered how easy it was for me to make quick (and negative) judgements from a position of privilege and power.

7.6 Final Word

This research has raised some questions and added to the debate about alternative forms of care and caregiving practices for children in large scale facilities in Bulgaria, particularly for children with impairments. However, although the findings relate to one section of one institution in one country, the findings can be used to inform ongoing debate, practice and policy making in this area beyond Bulgaria. Rassel and Smirnova (2014) point out that 'once a window for debate has emerged then recommendations and solutions can be developed'. Following this, I am developing my findings into a 'practical application' model to be used in institutions in Bulgaria which I am currently planning to 'try out' with one of the NGOs I have worked alongside. I deliberately attempted to interpret and understand the Babas' interactions as simply as possible in order to develop an 'alternative model' that could potentially be developed to use in other institutions. In doing so, I was particularly mindful that child development theories, and models of disability are not easily transportable, and therefore models should attempt to move away from context specific theoretical understandings. The simple elements; 'recognising, noticing and responding' in terms of the primary aspects of caregiving required for these children, can be more easily understood and allows for cultural differences and interpretations.

As I expected would be the case when I embarked on this exploratory research project, I have drawn some conclusions but I am still left with many questions. Coming to the end of a project like this will always involve uncertainty and reflections which include a focus on the 'gaps'. I have mentioned these in section 7.4 where I have

highlighted some areas of tension around research decisions, the literature I have used, the theoretical positions underpinning the study and my own reflections about the conclusions I have drawn. I have also highlighted what I feel to be the strengths of the project, especially in relation to my contribution to knowledge in the understanding of disabled children's experiences of institutionalisation in Bulgaria.

In chapter one, I introduced a quote by John Bowlby that was meaningful to me in embarking upon this project. However, in the introduction I left off the final part of the quote, which I am now adding (in bold) as it reflects my feelings as a researcher coming to the end of this work:

‘When people start to write they think they’ve got to write something definitive...I think that is fatal. The mood to write in is ‘This is quite an interesting story I’ve got to tell. I hope someone will be interested. **Anyway, it’s the best I can do for the present**’ (Bowlby, cited in Holmes ,1993:1)

To conclude this research project, and in keeping with my desire to forefront the voice of the Babas, I am giving the last word to Baba Ekaterina on behalf of her child Penka. Baba Ekaterina is the Baba who, with tears in her eyes during her interview, told me that when she first met Penka (a child with Down’s syndrome) she was nine years old and:

She could not do anything, she was only looking at the ceiling and the doors, expecting for someone to enter with a bottle. She even couldn’t turn around, only she was moving her head.

After four years together Penka is walking, eating solid foods, developing self-efficacy, observing other children and communicating with them, making noises to express herself, and able to understand her Baba’s directions and intentions. She also

spends time outside the institution in the swing park in the orphanage grounds and goes for walks with her Baba around the local community, which includes visiting the local shops. She shows jealousy when the Baba gives her attention to other children and when asked where her Baba is she points her out. This Baba and child relationship is the one mentioned by Bev (Vol), when she said, 'I did think to myself, well, they could be a real grandma and granddaughter'.

At one stage during her interview with me, with a tone and look of despair, Baba Ekaterina said, 'I know it will be impossible for somebody to listen to the Babas'. In response to her conviction that their voices will not be listened to, I include her quote as the concluding words to this thesis. When asked about the benefits of the Baba project for Penka she replied:

if there were no Babas the children would still be in the same condition as we found them. Penka will never have had the chance to walk, she would still be looking at the ceiling.

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Appendix 1

Extracts of Personal Diary Entries with initial reflections

1. new child

Horrible day today...I was in the playroom with volunteers L and K when the door opened and a young child (approx. age 2) was shoved into the room and the door was shut behind him. He looked terrified and was sobbing uncontrollably. His shaven head told me he was new to the home and obviously had no idea where he was. The other children didn't seem to notice. Volunteer L instinctively approached him and held him to her trying to soothe him. He allowed the close contact but didn't stop crying- he continued to look very traumatised. We offered our 'basic Bulgarian' in soothing tones but decided this was difficult without knowing his name. I went to find a nurse, brought her back to the room and pointed to him, asking 'what's his name'? She shrugged her shoulders and left the room only to appear a few minutes later to write his name in huge letters up the side of his arm. She held him roughly as she wrote the name using a biro pen, and had to press really hard on his skin as the pen wouldn't work properly. She was smiling. Throughout this experience he looked very obviously distressed but the carer made no attempt to ease this for him. When she left the room we had a discussion about how the carer appeared to have not 'seen' the child at all, how she had not appeared to be moved by his emotional state and how she appeared to have 'dehumanised' him.

My reflections: I pondered how some of the staff seemed able to switch off from the children- - this was also the topic of much conversation amongst the volunteers. This was not borne out of a need to judge them, but from a genuine attempt to understand that staff can also be institutionalised. This diary entry (and many other informal observations) triggered my thinking about Goffman's work on institutionalisation, specifically his thoughts on 'total institutions', the way institutions de-humanise the 'inmates'.

2. mirrors and identity

Thinking about the resources we brought- the mirrors have been an exciting experience for the children, especially in sectors 2, 3 and 4 (age gp 18mths to 4 years). When Child R (approx 2 years) saw himself in the mirror he was totally fascinated and started playing with his own face. He was pulling on his eyelids and his lips, stretching them and letting go, poking his tongue out, putting his mouth on the surface of the mirror, holding the mirror really close, then slowly moving it further from his face, lying on his back holding the mirror above his head looking down at himself through the reflection. Many of the children acted in a similar way, and with the help of the volunteers the children were beginning to realise that it was them in the reflection. This type of activity was extended for the older children by using a camera, taking pictures of the children and then immediately showing them back to the children on the playback screen. The children started to point to themselves and name themselves in the pictures.

For the older children we printed out some large pictures of every child and we displayed them around the playroom so that the children could see themselves. It was interesting that the older children (3-4 yrs) could name the other children in the pictures but most of them could not name themselves in the pictures. This led me to think that perhaps they had no experience of seeing reflections of themselves as the walls of the institution, including the playrooms, are bare, and the children have no experience of mirrors.

My Reflections: This entry also made me consider how children develop a sense of who they are from the messages given to them by others. In one conversation with a baba I noticed the little girl was wearing a 'garter' round her head as a headband, the colours of the garter matched the colours on her outfit and it was an obvious attempt by the baba to make the child look nice.

3. circle of Babas

Visit during summer 2010- going for a walk with volunteer B when she was upset and seeing the babas outside in the lane sitting in circle with the babies in buggies facing inwards. All of the babas were chatting and laughing to each other whilst also involving 'their' children in the social interactions. One baba had her baby out of his pushchair and was holding his hands as he walked, her back bending over him as carers typically do when helping a child to walk. They looked like any other bunch of grannies or parents out with their children. They were sitting in the shade laughing and chatting. This was the first time I had seen the children out side of the institution, they looked different, they looked more 'normal'.

My Reflections: The Babas are the only people who take the child 'out' into the community...making child more visible. This reminded me of Vygotskian concepts of the child learning the cultural tools, being part of their culture, learning language in a natural setting. links to Vygotsky child being part of culture, and learning language. Being part of the culture and wider communities. Role of adults in 'scaffolding' child eg. walking, and developing language from being immersed in language being spoken around them.

4. 'unrecognisable child

Child C – during my first visit March 2010, 5 months ago– one of the most distressing sights from my first visit (about 2 years old, fair haired little boy, sitting in playroom, shuffled to corner, very stressed, banging his head repeatedly off a wall, saddest eyes). 5 months later- I was waiting for the lift to take me from one part of the institution to another. I had just left one of the rooms because I was feeling upset about some of the interactions with a child and was therefore distracted. I was aware of one of the friendly Babas walking towards me with a child walking along beside her. They were approaching the lift. I kept my head down because I had been upset and didn't want her to notice that my eyes might look teary. I was aware of a little boy standing proudly beside his Baba, he was wearing a bright yellow hand knitted (chunky knit) cardigan, a pair of smart shorts pulled up high around his middle, fresh looking socks and shoes that appeared to fit his feet (not a common sight in the orphanage). The baba was chatting to him the whole time in a gentle and animated voice. He was not responding verbally but he was smiling. I was looking at him but not really noticing him, just taking in the overall scene of him having a nice time with his baba, I smiled at him and thought to myself how lovely he looked (obviously not wearing the institution clothes), and I smiled at his baba and said hello.

I looked away again and then suddenly realised that the little boy looked familiar and he was actually the little boy who 'haunted my thoughts' after my first visit. The little boy who could not be comforted, the boy with the sad, sunken eyes who sat rocking in the corner of the cold, tiled playroom and banged his head off the walls repeatedly for over an hour while all the other toddlers were clambering over us for bits of affection and contact. The little boy who the psychologist told me was 'autistic' and to not even try to comfort him because 'he hates human contact'. As I

realised this I obviously showed the surprise on my face and said 'child's name' in a questioning tone to the baba. The baba smiled, stroked his hair, and said 'yes' followed by 'child's name' (she seemed 'proud').

My reflections: Child development theorist Bronfenbrenner - 'every child needs to have someone in their life who is 'crazy' about that child'. I wondered about the role of the baba as that person. Also linked to Bowlby's theory on attachment and 'safe base' from which to explore...happy little boy holding the hand of his baba as he 'explored the world'. Using her for 'social referencing'...looking at me then to the baba for reassurance. Exploring the world, a bigger world than the child had previously known. How can the child develop an understanding of their world and begin to make meaning of it if they cannot actually explore it?

5. 'did he exist?'

I felt really sad today when Volunteer Hattie asked me about the life of Baby 'B'... he was here the last time we came out, tiny then (summer 2011, and still tiny now, Nov 2011), although his head now seems larger than his body. I had never seen a child with hydrocephalus before volunteering here, unfortunately he now looks like baby girl A who died recently. I felt inadequate when I went to pick him up and found myself unable to work out how to actually lift him whilst supporting his huge, heavy head and his tiny fragile body. Hattie had noticed me struggling and she probably saw my frustration. Hattie, so used to caring for him by now as she had been with him every day, picked him up confidently and brought him over to me. She passed him to me very carefully, explaining that he was at peace when being held...she said that he always stopped crying (if you could call his whimper a cry) when he was held. I had watched Hattie every day taking time out when no one else was around, to make sure he was clean and comfortable. She always hangs back at the end of the day to go and give him an extra cuddle before home time. Today, the last day of our visit, she hangs back for longer. I am watching her and she doesn't realise. She is leaning over the cot stroking his face gently. I am wondering what she is thinking. As she finished saying her goodbyes I realised she was crying. She knew she was saying goodbye for the last time, from our experience so far we both knew that this baby would probably die very soon. I left her in peace with her thoughts and she came out of the room after I watched her trying to 'pull herself together'. I gave her a hug. Later that night in the restaurant she started to ask me questions... the same questions I have asked myself since visiting the institution for the first time, and during every visit since, especially in relation to the children who appear to be 'untouched' by staff. Hannah asked me 'do you think it means he existed because I held him and talked to him every day?', does it mean he didn't exist if no-one mourns his death? How do we know he existed? How did he know he existed? I discussed this with her giving the best answers that I could think of. What else could I have said? Was I right when I said that her small offerings of cuddles, kind words, gentle feeding and responsive care had meant that 'yes' he had existed?

My Reflections:

Wondering about how we 'become' a person, and how this can be possible without others. We are only a 'someone' in relation to others. All of the messages children receive to support their development of who they are.

Appendix 2

Interview Guide - Babas

Tell me how you got involved with the Baba programme? What did you do before?

Tell me about the children you work with ?

What is your typical day like? What do you do?

How did you feel when you met the children for the first time? What could xxxx do?

What can xxxx do now?

What does xxxx like best about your time together?

What do you like best about your time together?

What was xxxx' s life like before having a Baba?

What difference is it making having a Baba? How?

If you could inform the policy makers what would you suggest for the children?

Would you like to add anything else?

Interview Guide – Professionals, NGO reps and volunteers

Tell me how you got involved with the Baba programme? What is your background?

Tell me about some of the children you/ or the Babas work with ?

What is their typical day like?

What can xxxx do since having a Baba?

What do the children like best about the time with the Babas?

What do the Babas enjoy?

What was life like for the children before having a Baba?

What difference is it making having a Baba?

Can you think about,, and tell me about one or two children who you feel have gained from having Babas?

If you could inform the policy makers what would you suggest for the children?

Would you like to add anything else?

Appendix 3



Professor Kathleen McCourt, CBE FRCN

Executive Dean

This matter is being dealt with by:

Education and Social Care

Faculty of Health and Life Sciences

Room C106

Coach Lane Campus West

Newcastle upon Tyne. NE7 7XA

Tel: 0191 2156464

Fax: 0191 2156404

14th Sept 2013

Dear XXXXXXXXXXXX

I am writing to seek your permission to carry out some research with some of the Babas who are working on behalf of 'organisation name' to support the children in Institution X.

I am a Senior Lecturer in Early Childhood at Northumbria University and I am currently enrolled on a Doctorate programme (PhD) with the intention to carry out research into the impact of the Baba programme on the children's development. In order to comply with Northumbria University's strict ethical procedures, and before I can begin this research, I must request your permission to carry out this research.

The research is intended to highlight the positive aspects of the Baba programme for the children, and I would hope that the findings of the research will also help to develop similar projects for other children in institutions in Bulgaria and in other countries. I feel this is a good opportunity to highlight an aspect of good practice for the children living in institutions.

The research would involve interviewing 6 babas about their role with the children to explore how they feel they have encouraged the children in their development. As well as interviewing the babas over a two week period, I will examine the documents held by your organisation which outline the children's progress since being involved in the programme. I would also like to interview two of the psychologists who are involved with the Baba programme, and I would like to interview you about your own role and your thoughts about the Baba programme. At a later date I will obviously seek further permission from the babas, the psychologists and yourself to be interviewed, at which point I will provide more detailed participant information packs.

I am happy to keep you informed of the progress of the research at regular intervals.

The research findings will be written up into my PhD thesis and may be summarised to present in academic publications and conferences, however, all data will be treated confidentially; the institution, the children, the babas and other participants will remain anonymous at all times.

I would like to assure you that this research study will be reviewed and will receive ethics clearance through the Research Committee at Northumbria University before I can begin my research. I do hope that you will grant your permission for this study to go ahead.

If you are happy to give your permission, please sign the statement below to confirm your consent.

Yours sincerely

Lindey Cookson BA (hons), MA Ed.

Senior Lecturer (Early Years)

Northumbria University

Faculty of Health and Life Sciences.

Tel. Work: xxxxxxxxxxxx

Mobile: xxxxxxxxxxxx

Statement of Consent

I understand the research project and I give my consent for Lindey Cookson to carry out research about the Baba Project which is managed by 'Organisation name'

Name

Signature

Role/ Position

Date

Appendix 4

Participant Information Pack - letter of invitation to participant



Dear

You know me as a volunteer in the institution as I have visited many times. I am currently studying for a Phd which aims to explore the role of the Babas in promoting the development of children in institutions. I would like to hear your views about how the Baba project makes a difference to the children. I am keen to interview you because you have a lot of experience working in this area.

If you would be willing to take part in my project please read the additional information sheet.

I would like to assure you that this research study has been reviewed and received ethics clearance through the Research Committee at Northumbria University.

If you have comments or concerns about this study please contact me.

Regards,

Lindey Cookson

Telephone- 0191 2156455 email lindey.cookson@northumbria.ac.uk

Participant Information Pack - Information Sheet



What is the research about?

The aim of this research is to explore the positive impact a Baba plays in the life and development of children living in the institution. I hope that this research could be used to promote the development of similar Baba projects in other institutions in Bulgaria and in other countries where children live in institutions.

What am I being asked to do?

I would like you to interview you about your work with the children during DATE for approximately one hour. A translator will be used.

Do I have to take part?

It is up to you whether or not you would like to take part and your decision will not be shared with anyone else by me.

What will happen to the interview material if I agree to take part?

The interview data will be treated as confidential and stored on a password protected computer in a secure location. The only person that will be able to access the data will be the researcher (Lindey Cookson). The data will be used to write my final project and some articles. The findings of this study may appear in publications and may be talked about at conferences but your identity will not be revealed. Your name and personal details will always be removed to protect your identity. All information you provide will be considered confidential and your names will not be used in anything I write. You will be offered copies of any published reports.

Are there any risks if I take part ?

There are no known or anticipated risks to participation in this study.



Who do I contact if I want to ask more questions about the research?

The researcher is Lindey Cookson and her contact details are:

Telephone number: 0191 215 6455

Email address: lindey.cookson@northumbria.ac.uk

Dr Colin Cameron is the Supervisor of this project .

His contact details are Colin.cameron@northumbria.ac.uk

Appendix 5

Participant Information Pack - Consent Form



Researcher: Lindey Cookson, School of Health, Community and Education Studies, Coach Lane Campus, Northumbria University, Newcastle-Upon-Tyne, NE7 7XA. Email: lindey.cookson@northumbria.ac.uk

This form is designed to confirm that you have been fully informed about the research, that you know what you are being asked to do, and that you consent to taking part in the research. Please tick the columns below and sign at the bottom of the page.

	Yes	No
I confirm that I have been given and understood the information sheet for this study and have received answers to any questions raised		
I understand that my participation in the research is voluntary that I can withdraw from the research at any point without giving a reason		
I am aware that any personal information will be kept securely and in confidence and will not appear in any printed documents		
I agree to be interviewed		
I agree to be audio-recorded during the interview		
I understand that my words may be quoted in publications, reports and other material but that they will be anonymised so that I am not identifiable		
I have been given the contact details of the researcher who I can contact if I have any further queries about the research		
I would like to request a summary of the research to be sent to me		

Name:

Signature:

Researcher name:

Researcher Signature:

Date: